

THE UNIVERSITY OF CHICAGO

FIGURING FAMILIES: CAREGIVING IN THE MIDST OF ALZHEIMER'S DISEASE

A DISSERTATION SUBMITTED TO  
THE FACULTY OF THE DIVISION OF THE SOCIAL SCIENCES  
IN CANDIDACY FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

DEPARTMENT OF COMPARATIVE HUMAN DEVELOPMENT

BY

AARON TODD SEAMAN

CHICAGO, ILLINOIS

AUGUST 2016

Copyright © Aaron Todd Seaman  
All rights reserved.

For my family;  
and in memory of Dale Brashers.

## Table of Contents

Acknowledgements	v
Abstract	x
Introduction	1
Chapter One: Finding Alzheimer's Disease in the Family	37
Chapter Two: Alzheimer's Live Here: The Ecological Niche of AD and Family Caregiving	76
Chapter Three: The Consequences of Doing Nothing: The Non-Action of Care in the Logic of the Coming Cure	120
Chapter Four: Five More Years: The Temporality of Hope	151
Chapter Five: Shifting Intimacies and the Flexibilities of Family Relations	177
Chapter Six: Forgetting the House: Making and Unmaking Families and Homes	202
Conclusion	232
Bibliography	237

## Acknowledgements

I have spent too long not writing these acknowledgements. At the end of it all, I fear I can not do them justice. Over a decade, one accrues a great deal of debt, and I know full well a few pages are far from what would be necessary to acknowledge the years of experience, mentorship, friendship, support, and kindnesses. Yet, as I am coming to terms with in all things academic and otherwise, the end's shortcomings are never a reason to forego beginning attempts. And this dissertation and the research on which it is based is the result of so many people's efforts, to all of whom I am forever indebted.

This dissertation quite literally would not be without the people whose experiences populate these pages. Although I will not name them here in an effort to protect their privacy, I am so grateful to them. The families with whom I was lucky enough to work welcomed me into their daily lives, their homes, their support groups, their meals and chores and conversations, their challenges and celebrations. Through it all, their openness, reflexivity, and generosity were boundless. The same holds true for the members of the medical community who agreed to participate in my work, especially those affiliated with the Memory Clinic and its support group. Whether in clinic, at a training for long-term care facility employees, attending a conference, or in support group, they opened their doors and shared their expertise. In the midst of their always-overburdened schedules, they never appeared too busy to field yet one more question from me. They may sit mostly at the margins of the writing here, but their influence wends all through the narrative.

Throughout this work, my committee has been a constant and fertile source of mentorship, and the moments of the dissertation that work well are the result of their intellectual

generosity and guidance. Before I started my graduate work at the University of Chicago, I had a conversation with E. Summerson Carr that I still remember as a key moment in my decision to attend. From that day, she has been an intensely engaged interlocutor, always asking the question or making the comment that expanded my thinking in new directions that I could only account for long after the conversation. Judith Farquhar's excitement about and generous support of my project has been both (in a moment of positive contagion!) infectious and critical in making connections to the larger endeavors of medical anthropology and intellectual inquiry. My far-ranging and interdisciplinary conversations with Eugene Raikhel about care, expertise, and the relationship between medical and domestic domains have been indispensable; he has that rare ability to offer focus and direction that supports and strengthens one's intellectual trajectory rather than imposing his own, a quality I greatly appreciated as I worked to articulate my own perspectives. Most deeply, I am grateful to my adviser Jennifer Cole, whose unwavering faith in me as a scholar has been so critical. Prior to joining the Department of Human Development, my background was in neither anthropology nor human development. That today I am an anthropologist and a scholar of human development is due to her support and guidance.

In addition to my committee, I also have benefited from the expertise, time, and assistance of numerous faculty across the University of Chicago: Bert Cohler, Robert Fairbanks, Micere Keels, R. Tamara Konetzka, John Lucy, Joseph Masco, Martha McClintock, Richard Shweder, Eric Slauter, and Richard Taub have all engaged this work at different points. The University of Chicago supports a vibrant, interdisciplinary workshop system, and this work has grown immeasurably as I have shared portions of it in the *Medicine, Body, and Practice*

workshop; the Clinical Ethnography workshop; and the US Locations workshop. And always, the administrative support of Janie Lardner and Spencer Bonadeo has made all tasks easier.

Of course intellectual engagement is never bound within the walls of any single institution. I have been welcomed by so many people across the broader academic community. During my master's work at the University of Illinois, Urbana-Champaign, I was lucky to work with Dale Brashers. Although he passed away in 2010, his imprint on me is indelible. He was the kind of scholar and mentor I aspire to be, always knowing I will fall short. Michele Koven also was a guiding presence during my time there, introducing me to anthropology and eventually directing me toward the Department of Comparative Human Development. At the Society for Medical Anthropology conference in 2009, I was fortunate to meet Janelle Taylor, who since has been a constant mentor and interlocutor, a partner in research on dementia and care. Janet Carsten, Lawrence Cohen, Sharon Kaufman, Sarah Lamb, Annette Leibing, Margaret Lock, Elizabeth Mertz, and Elizabeth F.S. Roberts have all been wonderful enough to discuss portions of this work, either on conference panels or in personal conversations emerging from them. This work also has benefitted from extended, generative discussions in an ethnographic writing seminars both with Jennifer Cole at the University of Chicago and with Gillian-Feeley Harnik in the Department of Anthropology at the University of Michigan, which generously allowed me to participate in its academic life as a visiting scholar. Early versions of chapters five and six were also presented at the 2013 Cascadia Seminar in Medical Anthropology and the Wits Anthropology Seminar in the fall of 2014. Across forums ranging from classrooms to parks, panels to pubs, both my scholarly development more broadly and this research in particular have been shaped by the collegiality of so many, for whom this list is almost certainly incomplete:

Adam Baim, Dan Birchok, Robert Blunt, Betsey Brada, Beth Brummel, Julia Cassaniti, Michael Chladek, Amy Cooper, Jason Danely, Robyn D’Avignon, Bianca Dahl, John Davy, Christine El Ouardani, Kathryn Goldfarb, Laine Goldwert, Rebecca Graff, Brian Horne, Kelda Jamison, Emily Johnston, Fred Ketchum, Abbe Rose Kopra, Hallie Kushner, Zhiying Ma, Kate Mariner, Meg Mass, Marlee McGuire, Kathryn McHarry, Todd Meyers, Erin Moore, Emma Nolan-Thomas, Cyrus O’Brien, Ender Ricart, Ashley Rockenbach, Michal Ran Rubin, Jonah Rubin, Nafisa Essop Sheik, Yvonne Smith, Stephen Sparks, Matt Spitzmueller, Anne Stone, Gregory Thompson, Liz Timbs, Marieke van Eijk, Talia Weiner, and Emily Yates-Doerr. And always, keeping me afloat through everything, has been my writing group, the current iteration of which is Elana Buch, Laura Heinemann, Julia Kowalski, Jessica Robbins-Ruskowski, and Kristin Yarris. Julia called “writing group” too anemic a term to encompass all we share, and I have to agree.

The research on which this dissertation is based was carried out with funding from the National Science Foundation and the Wenner-Gren Foundation for Anthropological Research. The writing was supported by a dissertation fellowship from the University of Chicago’s Social Sciences Division.

At the heart of this dissertation is family, not only thematically but also practically. These past several years would not have been possible without the unfailing support and encouragement of my own family. My parents, Cindy and Paul Seaman, who have always made all things possible, have done so once again. Brady G’sell, my constant companion, we have done so much these past sixteen years, of which this is but one small part. There is no possible way to express my gratitude for all that you do and are; I can only hope that you already know.

And Isla Seaman G'sell, I was once told that "children leaven the loaf of academic life";  
thankfully, with you, I found out that it is true.

## **Abstract**

In 2015, an estimated 5.3 million people in the United States were living with Alzheimer’s disease (AD). For both those diagnosed and their families, the dominant narrative of what this life is like is a harrowing one: Alzheimer’s disease is a terminal condition that unremittingly eats away at people’s ability to connect with the world around them, slowly unraveling the core of who they are. There currently is no known cure, and existing pharmacological treatments have limited, short-term benefits. Family members—most often, spouses or children—become the primary caregivers, tending to the daily needs of those diagnosed with Alzheimer’s. Given the lack of possible medical intervention, they must focus their efforts on maintaining the comfort, dignity, and quality of life of those diagnosed. A political climate of scarce resources and a biomedical logic that privileges the eventuality of a cure, however, frame families’ efforts as burdensome stop-gap measures that do nothing to halt Alzheimer’s progression. In this paradoxical milieu, where caregiving is both seen as critical to national health care infrastructure and deeply devalued, families must provide care and continue the familial work of social reproduction.

Through a study of couples living with early-onset Alzheimer’s disease in the Midwestern United States, this dissertation examines how families learn to live with Alzheimer’s, the ways they balance a caregiving relationship with existing family relations, and what the implications of doing so are for them as a family. Medical anthropologists and sociologists frame the process of learning to live with illness as one of increasing medicalization for those involved. Viewed in this way, life with Alzheimer’s is a process of becoming a “person with Alzheimer’s disease” and a “family caregiver,” a trajectory in which families are dissolved

into this new relation—one often understood by scholars as primarily one of social control—as biomedical understanding comes to obscure all other relational possibilities. In contrast, I argue that families draw upon both biomedical and familial notions of AD and caregiving as they learn to live with Alzheimer's. Even as they increasingly recognize themselves in terms of a caregiving relation, I demonstrate that family members remain concerned with endeavors of family-making. The familial work of social reproduction does not fade, but rather is a critical part of the caregiving relationship as families learn to live with AD. Families labor to maintain these endeavors in the midst of life with a condition understood to unravel the very abilities of relationality considered necessary to maintaining family. In my fieldwork, I found that they did so by learning to recognize AD, generally considered a condition of the brain, as a disease entity constituted in the social and material relations of family. Across the dissertation, I trace the ways that, by engaging in the work of kinship and family-making, family members are able to, even temporarily, act upon and rework Alzheimer's disease.

My research contributes to work in anthropology, sociology, and science studies by, first, retheorizing the relationship between the clinic and the family. I argue that medicalization is insufficient to conceptualize the processes of learning to live with AD. As much as families living with AD come to understand their family in medicalized terms of Alzheimer's disease and caregiving, they also come to understand Alzheimer's disease and caregiving in terms of family, not only their own family history, relations, and narratives, but also more dominant ideologies and understandings of family that circulate in US discourse. Through the practices and relations of everyday family life, I argue, families *domesticate* Alzheimer's and caregiving. Alongside theories of medicalization, domestication illustrates that both Alzheimer's disease and family

caregiving are shot through with ideologies of family, its relations, routines, and practices, and the obligations it engenders. Further, it accounts for the fact that Alzheimer's and caregiving enter people's lives *in media res*, that people don't adopt them wholly—no matter how encompassing them can seem—but instead incorporate them into the larger projects of their lives. By shifting the frame to one of domestication, I both unsettle the clinic's dominance in shaping people's understandings of health and illness in their own lives and dispel any clear boundary between the biomedical and the domestic.

Second, by conceptualizing family caregiving as a sociohistorical formation of knowledge, practices, relations, and morality, I offer conceptual clarity within theorizations of care. In contrast to the less culturally and historically situated “care,” I argue that family caregiving is a phenomenon unique to the late 20<sup>th</sup>/early 21<sup>st</sup> century US, situating caregiving as the product of a particular time and place, rather than a naturalized enactment of ahistorical family obligation. In doing so, I foreground the explicit nature of the way family care labor is drawn upon within the health care system, tracing how political economic concerns about care and aging filter into the daily lives of families, transforming them. In addition, I highlight the relationality of the processes I examine through a focus on family caregiving, drawing attention to the way that all parties are subjected to the discourses and moral frameworks of family caregiving. Too often, given the perceived vulnerable nature of dependency, care is articulated as a practice or relation of dichotomous domination, wherein one person or group exerts controls over another person or group. However, the relations of caregiving I examined were much richer than a narrative of social control could encompass.

The body of the dissertation comprises six chapters, loosely structured into the three sections. The first section, chapters one and two, illustrates how families come to see Alzheimer's disease in the midst of their daily lives. In chapter one, I focus on the diagnostic process within the clinic. I argue that, despite a great deal of concern over locating Alzheimer's disease as a pathological process within the brain, the condition is seen most clearly within the daily lives of those diagnosed. Families are calibrated as a type of diagnostic technology to observe and report upon the moments of everyday life when Alzheimer's becomes visible. As they do so, they come to see AD within the social and material relations of family. The diagnostic process is one of locating Alzheimer's within a person's home and community, and the second chapter examines what "comes home" with the diagnosis, namely conceptualizations of Alzheimer's disease and family caregiving that come to shape how families understand their lives. I trace the entangled emergence of AD and family caregiving through the entrenched narrative of Alzheimer's activism, the dominant symptom of memory, the understanding of both AD and caregiving through activity, the powerful temporality of decline, and the structuring logic of a coming cure. As families learn to see Alzheimer's and family caregiving through these lenses, their relations are altered.

Chapters three and four compose the second section, detailing how families are affected by the dominant conceptualizations outlined in the previous chapter. In chapter three, I argue that the biomedical privileging of only action directed toward the search for a cure as meaningful and legitimate renders the work that families do as *non-action*. In contrast to inaction, or passivity, non-action can involve a great deal of action, but action without meaning. The everyday labor of both those diagnosed and family caregivers—to maintain themselves and each other—is obscured,

a devaluation that families come to adopt. Chapter four shifts the focus from the possibility of action within the logic of a coming cure to the disconnect between its hype-filled temporality and the temporality of inexorable decline. Focusing on families' perceptions of clinical research, it offers a potent ethnography of the disjuncture between biomedical agendas and the lived realities of families, tracing the ways that the construction of hope on a national scale of research and activism can attenuate hope on another, smaller scale—that of families.

The final section, chapters five and six, examine how families, even as they employ the dominant biomedical conceptualizations of Alzheimer's and family caregiving, also draw upon familial relations, practices, and spaces to make sense of their lives and to continue their endeavors of family-making. In chapter five, I examine how family caregivers find flexibility within their understandings of kin relations in order to maintain relationships commensurate with caregiving and family. Whether coming to think of their spouse as a child or of the roles of their spousal relationship as flipped, I demonstrate that family caregivers employ a range of understanding of roles, activities, and intimacies to continue to conceptualize the diagnosed person as family. In doing so, in contrast to notions of infantilization, I argue that families' use of alternative kin understandings can be a means of maintaining family and personhood, rather than doing violence to them. Chapter six broadens the frame to include material relations, namely the relations between family and home. I argue that as a family comes to see Alzheimer's disease within their home, the home becomes a site for intervention, where action can be taken to stave off the effects of Alzheimer's. Yet, as changes are made to the home, Alzheimer's becomes increasingly visible, threatening the stability of the family. Ultimately, I illustrate, families work

to disentangle the social relations of family from the material ones, recasting family across new spaces beyond the home.

## **Introduction**

### **Plastic Forks**

The dining hall of the suburban church was bustling, especially for a weekday morning. Conversations from several directions bounced off the high ceiling, the large, sunlit windows along one wall, and the doors to the chapel opposite. I stood to one side near the food, taking in the swirl of activity. This was one of my early visits to the Memory Clinic's support group, and I maintained a slight unfocus, trying to absorb as much as possible from as many different directions.<sup>1</sup> People sat around several large, round tables, couples mostly, talking and drinking coffee or tea. Others gathered up front, removing and hanging their coats, collecting their name tags, or talking with the group's small staff. Still others waited in line near me, looking over the counter covered in baked goods, plates, and napkins, and carafes of coffee and tea. As I watched, I tried to notice what made the gathering different from others held at the church; I tried to notice the Alzheimer's disease (AD) that brought everyone together.<sup>2</sup> Yet, what struck me was how ordinary the scene was.

---

<sup>1</sup> In order to protect the privacy of my informants, the names of all places and people throughout the dissertation, except when they have specifically asked otherwise or when they are public figures, are pseudonyms.

<sup>2</sup> On this side of my research, it seems naive even to write this. Yet, at the time, I'd had little exposure to Alzheimer's other than what seems to circulate in the US, a form of discursive pollution one can hardly avoid. It's the kind of pollution that makes the quip about losing one's keys signaling the loss of one's mind immediately recognizable. As others have written, its genre is horror, conjuring fear of loss of control, dependence, of being forgotten in a wheelchair in the corner, trapped in one's mind, or worse, lost without it (e.g., Bastings 2009; Cohen 1998; Gubrium 1986; Herskovits 1995; Taylor 2008). My one personal connection—my grandmother's sister had been diagnosed with AD, but we didn't see her much while she lived with it—only confirmed this notion. Her daughter, with whom she'd always been incredibly close, related moments when the now bed-bound woman spat on her, telling her she was worthless, that she'd done nothing to help despite years of closely attending to her mother's needs.

While I waited for the opening portion of the meeting to wrap up and everyone to separate to the breakout groups where the “real work” happened, a middle-aged man, whose name I would later learn was Mark, walked up to the food counter, looking slightly distracted. He glanced back at the table he’d just left, where a woman I assumed was his wife waited, bringing his attention back to the counter only as he came to it. Another staff member, Debbie—a jovial woman who ran one of the family caregiver breakout sections—was behind the counter, passing out slices of a store-bought yellow cake that the staff had brought in celebration of the group’s fifth year. She handed Mark two slices on small paper plates, chatting with him as she did so, asking how he was doing, how was his wife. He looked around the counter briefly and asked if there was any silverware for the cake. Debbie raised her eyebrow, looking at him quizzically, and then pointed down to a wicker basket sitting between them, filled with clear plastic forks. A pause, and then they both laughed. “It’s like a test,” he said, remarking on the invisibility of the clear utensils, “to see if I’m still doing okay, huh?” Chuckling, she agreed, “You got it—‘Can you find the silverware?’ That’s how we tell which room you need to go to!” The moment ended, and Mark grabbed the two dessert-sized paper plates, along with two forks, and headed back to the table where his wife Elise waited. He set both plates down as he sat down next to her. Together they ate their cake, he talking outside my range of hearing and she mostly listening and watching the others at their table, occasionally smiling or adding a comment to the conversation.

That morning, I was struck by the joke itself, the seeming crassness of it, calling attention to the fact that some in the room—those diagnosed with Alzheimer’s—were not “doing okay.”<sup>3</sup> Although I didn’t know it yet, this kind of gallows humor was common among the people with whom I worked. And, while one understandably might assume that these moments of levity were at the expense of those diagnosed with Alzheimer’s disease, those with diagnoses often were the ones telling the jokes. Laughter often could be heard from outside the breakout sessions of diagnosed persons as they talked about what their lives with Alzheimer’s were like.<sup>4</sup> Rather than targeting the person, conversations at support group meetings or more casual gatherings often were punctuated with laughter at Alzheimer’s expense. Jokes about things forgotten or social gaffes became opportunities for diffusion, when, for a moment, what it meant to live with Alzheimer’s disease could be reframed as something other than tragic.

Over time, however, I keep coming back to this small exchange between Mark and Debbie because of the way it quickly, if subtly, articulated Alzheimer’s disease and family caregiving. Both came into being in the midst of their interaction over a slice of cake.

Alzheimer’s was present in the room before that moment, certainly, circulating diffusely as a generalized knowledge that it was the reason everyone was there. But AD is understood as

---

<sup>3</sup> Throughout the dissertation, I refer to people who have been diagnosed with Alzheimer’s disease as “people diagnosed with Alzheimer’s disease,” “those diagnosed,” or “diagnosed people” in order to emphasize that, alongside any physiological changes one may be experiencing, a rich and largely overdetermined social imaginary is conferred upon those diagnosed through processes of medicalization. In this way, “diagnosis” is a kind of a shorthand for “recognition,” standing in for the persistent recognition of people living with Alzheimer’s disease through the lens of that imaginary—by policymakers and advocates, researchers, the media, clinicians, families, and those diagnosed themselves.

<sup>4</sup> One month, a gentleman introduced himself by saying, “I’m sixty-seven years old, and I’ve been having memory issues for probably—I wanna say I forgot, but over a year, I’d say.”

inherently difficult to spot, especially among those whom the medical community would categorize as having early-stage Alzheimer's or even mild cognitive impairment, a condition of minor cognitive troubles that is regarded as often a precursor to AD. People frequently recount drawn-out periods of misdiagnosis—stress, for example, or depression, even menopause—before they or their family member has received a diagnosis of Alzheimer's disease. Janis, a social worker and the de facto director of the XO Memory Clinic's support group, more than once recounted a story to me about two diagnosed people who accidentally found themselves a breakout section for family caregivers. No one noticed, including the section's moderator, until the two announced during introductions that they had AD. From that point on, Janis, who printed name tags for all participants, made sure to underline the last name of those with the diagnosis so staff could be sure to direct them to the correct breakout section.

That morning as Debbie and Mark joked, however, the condition concretized and became visible in easy-to-miss clear plastic forks. One of the symptoms of Alzheimer's disease is a change in visuospatial abilities, the ability for a person to process what she<sup>5</sup> sees. People diagnosed with AD often will have difficulty with spatial relations, depth perception, or object differentiation. A bold, dark-colored pattern on a rug can become a series of holes in the ground. One can misjudge sitting in a chair. Or clear forks can be invisible.

A relationship of caregiving also was indexed through their conversation. The still “doing okay” family members were caregivers, their role marked by the breakout session they attended, as Debbie noted, as well as by the tasks to which they attended. While people diagnosed with

---

<sup>5</sup> Throughout the dissertation, when a pronoun has no specifically gendered antecedent, I use the female gendered pronoun. Occasionally, I switch between male and female gendered pronouns for stylistic reasons (e.g, if more than one person is referred to in the phrase or sentence).

AD often would make up their own plates of snacks, the joke's implication was that, at some point, the task was more appropriate for family caregivers. Daily activities such as plating food became primary points of practice through which relations of caregiving were structured. Through the act of getting cake, Mark became a caregiver. And Elise became a person with Alzheimer's.

Later I would note other markers, ones which bound medicalized condition and intervention together in social and material relations: who helped whom removing and hanging up coats, when people went to the bathroom alone and when they were accompanied. I would see how some people walked or the care with which others dropped into their seats. I would come to recognize Alzheimer's and family caregiving not in dramatic social breakdowns of "lost persons" but in quotidian, often domestic moments of daily life.

This dissertation studies couples living with early-onset Alzheimer's disease in the Midwestern United States in order to examine how families continue projects of family-making in the midst of learning to live with AD, a condition understood to dissolve the abilities of relationality that are precisely those critical to maintaining families. There currently is no known cure for Alzheimer's, and the few pharmacological treatments that do exist often have limited, short-lived effects. Families experience medical treatment as lacking efficacy, especially since they understand medicine's role of medicine as primarily one of intervention, of being able to fix and restore or, at least, maintain. Given the lack of effective medical intervention, family members—most frequently, spouses or children—act as the primary caregivers for persons diagnosed with AD across the course of their condition. A political climate of scarce resources, however, privileges the eventuality of a cure and frames families' efforts as burdensome stop-

gap measures that do nothing to halt the progression of Alzheimer's disease. In this paradoxical milieu where people and policies both depend upon and deplore family caregiving, families must provide care and continue the work of family maintenance.

Through the dissertation, I argue that, at the same time as families living with AD come to understand their family in terms of Alzheimer's disease and caregiving, they also come to understand Alzheimer's disease and caregiving in terms of family, not only their own family history, relations, and narratives, but also more dominant ideologies and understandings of family that circulate in US discourse. I demonstrate that, while families provide the majority of care to people living with Alzheimer's, they do not naturally understand themselves as "caregiving." Rather, they come to see themselves as caregivers through medicalizing processes that rework social relations. As families reorient, they learn to understand their situation as living with Alzheimer's disease—one member becomes the diagnosed, while the others become caregivers. Yet, this is more than a narrative of medicalization. Families are medicalized, certainly, but in the process, they also domesticate both family caregiving and Alzheimer's disease. They draw upon blended notions and ideologies—of medicine and what it should do; of Alzheimer's and its effects; of the objects of care; of what constitutes family—as they engage in caregiving.

While Alzheimer's disease and family caregiving are a prominent part—and often the dominant part—of families' daily lives, I demonstrate that they are only one part. Prior to diagnosis, families are in the midst of the labor of family-making, an on-going, continually reproductive process. While families view some of this work as grander in scale, involving the constitution, reconfiguration, or dissolution of relations as people were born, moved out,

married, divorced, died, a great deal of it comprises the labor of daily life—going to work, coordinating shower schedules, making and eating meals together, household chores, short moments of conversation, walking the dog. Learning to live with Alzheimer’s disease, I argue, is as much about the continuation of these family-making projects in the wake of diagnosis as it is about coming to interpret their lives through a medical lens. And as families work to fold Alzheimer’s disease into their lives, both it and family caregiving are affected by their engagement in these projects. Families, in a very real sense, make Alzheimer’s disease and family caregiving as they live with them.

Building from the ethnographic data, I develop a larger theoretical argument about the relationship between the clinic and the family and the role of medicine in family’s lives. Drawing together scholarship on kinship, care, and medicalization, this dissertation contributes to medical, and more broadly cultural, anthropology in two key ways. First, I retheorize the relationship between clinic and subject that undergirds theories of medicalization, proposing an alternative framework of domestication. As a means of understanding how something comes to be understood in medical terms and the effects of that understanding, theories of medicalization provide a powerful lens for making sense of large swathes of the phenomena of Alzheimer’s disease and family caregiving. Medicalization articulates the definitional power of medicine, critically through the production of disease categories and diagnosis. It focuses attention on the inherent power dynamic of medical relations. As theorized in medical sociology, it accounts for the historical trends of medicine and its practice in the US across the twentieth century. Yet, medicalization can only explain these phenomena as a movement from the clinic outward, the narrative driven by the power of medical authority and discourse. A shift in perspective to

domestication recognizes the same power, but as part of a larger circulation of understandings, discourses, relations, and practices. It accounts for the fact that Alzheimer's enters people's lives *in media res*, that people don't adopt it wholly—no matter how encompassing it can seem—but instead incorporate it into their larger endeavors.

By tracing both AD and family caregiving arise through processes of domestication, I do not presuppose boundaries between the medical and the domestic. In contrast, I demonstrate how Alzheimer's and caregiving emerge across clinical and familial settings as people draw on hybrid knowledges and practices to enact them. Conceptualizing AD and caregiving as enactments, I highlight the tensions between medical and domestic orientations, but do not reify them as domains.

Second, by focusing on family caregiving, I provide conceptual clarity within theorizations of care. I argue that family caregiving is sociohistorical formation of knowledge, practices, relations, and morality. Doing so has four benefits within a discussion of an anthropology of care. One, by historicizing the phenomenon as unique to the late 20<sup>th</sup>/early 21<sup>st</sup> century US, I situate caregiving as the product of a particular time and place, rather than a naturalized enactment of ahistorical family obligation. Two, caregiving, rather than care, also foregrounds the explicit nature of the way family care labor is drawn upon within the health care system. In doing so, it traces how political economic concerns about care and aging filter into the daily lives of families, transforming them. Three, a focus on family caregiving highlights the relationality of the processes I examine. In doing so, I draw attention to the way that all parties are subjected to the discourses and moral frameworks of family caregiving. Too often, given the perceived vulnerable nature of dependency, care is articulated as a practice or relation of

dichotomous domination, wherein one person or group exerts controls over another person or group. However, the relations of caregiving I examined were much richer than a narrative of social control could encompass. As a fourth point, however, I also position my work in contrast to scholars whose projects might be described as articulating “an anthropology of the good” (Robbins 2103), I see neither my own project nor my informants as one primarily concerned with caregiving as a moral endeavor, but rather as an attempt to make sense of the day-to-day efforts of family-making.

### **Living with Alzheimer’s Disease: AD, Family Caregiving, and the Logic of the Coming Cure**

The daily lives of families who live with Alzheimer’s are embedded within the medicalized context of an impending Alzheimer’s disease crisis. In 2015, an estimated 5.3 million people in the United States were living with Alzheimer’s disease, a number that is projected to triple in the coming decades (Alzheimer’s Association 2016). Through my research, I traced how families brought Alzheimer’s disease and family caregiving into their homes, how they did so differently, depending on the particularities of their family, and how living with Alzheimer’s changed them. Both spouses came to understand themselves through a medical lens. This medicalization involved coming to understand their lives not only in terms of Alzheimer’s disease but also family caregiving. As families did so, they sought to reconcile tensions inherent in both.

The object of Alzheimer disease differs depending on the viewpoint and its context.<sup>6</sup> Over the course of the following pages, Alzheimer disease will shift as activists and policymakers, researchers and clinicians, and families work to eradicate, understand, treat, and live with “it.” It will be a pathological condition of neuritic plaques and neurofibrillary tangles, the rippled path

---

<sup>6</sup> Rather than what Alzheimer’s disease is, I focus on what Alzheimer’s disease does, how particular understandings of it—as a medical condition, as something that must be cured, as an inevitable decline, as a disease that destroys people’s ability to maintain social relations—affect the way that people, families and especially spouses here, sustain relationships. In doing so, I draw upon Annemarie Mol’s conception of multiplicity. In her work, *The Body Multiple* (2002), Annemarie Mol theorizes a move from the epistemological question of how objects are known—a question which assumes a reality—to a discussion of how they are enacted. This, she argues, becomes an ontological discussion concerned with what object emerges through these enactments. It is a question of practices. “If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come into being—and disappear—with the practices in which which they are manipulated. And since the object of manipulation tends to differ from one practice to another, reality multiplies” (5). Yet, far from fragmenting and falling apart through this multiplication, “these [different versions] somehow hang together”:

A single patient tends to be supplied, if not with a single disease, then at least with a single treatment decision. Clinical findings, pressure measurements, social inquiries, duplex outcomes, and angiographic images are all brought together in the patient’s file. Together they support the conclusion to treat invasively—or not to do so. (84)

Mol refers to this understanding of multiplicity as “manyfoldedness,” where the folds must be coordinated, hanging together enough to enable intervention (*ibid*).

To conceptualize the emergent, interactional nature of Alzheimer’s disease (and, in turn, family caregiving), I also take inspiration from Summerson Carr’s discussion of enactments of expertise (2010). As she writes, in contrast to a body of work that describes expertise as a kind of knowledge object (e.g., Collins and Evans 2007), “Expertise is something people do rather than something people have or hold” (18). Carr’s conceptualization of enactment is particularly useful as she focuses on the emergent nature of expertise through the enactment. As she writes, “[E]xpertise is inherently interactional because it involves the participation of objects, producers, and consumers of knowledge. ...[It] emerges in real-time interaction as actors and institutions struggle to author and authorize powerful texts that will be read by others” (18, 19). This focus on emergence through interaction is critical to understanding Alzheimer’s disease as it places the condition not between one’s ears but between one’s relations. Further, the relations were it most prominently emerges are, as this dissertation demonstrates, not in the clinic, but in the daily lives of those diagnosed and their families.

of which can be tracked through an atrophying brain and seen in the decreasing cognitive functionality of a person diagnosed with AD. From a public or global health point of view, it will appear as an impending crisis, the result of too many dependent bodies in need and too few able bodies to provide. It would be the opportunity of a lifetime for the pharmaceutical company able to crack the code of its “cure.” For advocacy groups, it will be rendered in nightmarish terms, Lawrence Cohen’s “Alzheimer’s hell” on a both a personal and population level (1998). Those invested in the project of “person-centered care” will see Alzheimer’s primarily in the breakdown of social relations that can have devastating effects for those diagnosed as they are mistreated and marginalized by those around them. Between these different versions, tensions exist, and even the most successful instantiation of Alzheimer’s is unstable (Moser 2008). Many groups are able to narrow their focus, sidelining inconvenient versions. Families engaged in caregiving, however, are the ones who must find some way to make sense of this multiplicity. Families dealt with not just with *an* Alzheimer’s disease, but with multiple variations—the AD of brain pathology, the AD of changed social and material relations, the AD of public health crisis. Families had to learn to make sense of these different versions, to reconcile the tensions between them. They must find some way to make a version of Alzheimer’s disease “hang together” for them in order to act upon it and live with it.<sup>7</sup>

Given its prevalence in the public imaginary, families almost always have an understanding of Alzheimer’s prior to diagnosis. The US public imaginary of AD is powerful and haunting, and after four decades of discursive reinforcement in medicine, advocacy, policy,

---

<sup>7</sup> In Mol’s rendering, we see this work happen in the hospital, as a body becomes multiple bodies when moving across the different spaces of diagnosis, prognosis, consultation, and treatment.

and popular media, it is deeply entrenched. Alzheimer's is understood as a terminal condition that transforms every aspect of a person's life as they slowly succumb to it. Both hers and the lives of those who know, love, and/or care for her are irrevocably changed. A person with Alzheimer's loses her memory and cognitive function. Her sensory perception is altered, and she undergoes severe emotional and behavioral changes. Her ability to construct and maintain social ties unravels.

Families understand these changes as inherently medical, a condition of a brain gone awry, dying slowly as its neurons are choked. Although the specifics of Alzheimer's pathology as described within the medical community most often are less well understood, families use the language of "plaques and tangles," which seeps into the vernacular of those acquainted with AD through clinical interactions, caregiver materials, and support group discussions.<sup>8</sup> Through a process of diagnosis, these plaques and tangles are connected to the series of events in their or their family member's life that led them to seek medical consultation. Over time, they calibrate

---

<sup>8</sup> Biomedically, Alzheimer's disease is considered both a clinical and a pathological entity, joined through the process of diagnosis. Clinically, Alzheimer's disease is understood as one type of dementia. Dementia is a diagnosis based on what can be made visible through the series of examinations, tests, and interviews that compose the clinical examination. A diagnosis of dementia indicates the presence of a set of symptoms severe enough to interfere with a person's daily life. Along with memory loss, symptoms must include at least one of the following: difficulty with language (aphasia), recognizing or identifying objects (agnosia), motor functioning (apraxia), or executive function (e.g., planning, sequencing or organizing, abstracting) (American Psychiatric Association 2000). Alzheimer disease is understood as a pathological entity that is the most prevalent cause of dementia, reportedly accounting for upwards of sixty to eighty percent of dementia cases (Alzheimer's Association 2016: 461). As the first description above notes, Alzheimer disease is characterized by the development of neuritic plaques and neurofibrillary tangles (the result of accumulations of beta-amyloid and tau proteins, respectively), which lead to neuronal death and brain atrophy. Clinically a person is diagnosed with "possible" or "probable" Alzheimer disease, a diagnosis which is then either confirmed or dismissed upon posthumous examination of the brain tissue.

to see moments of forgetting or unsteady walking or lost words as indications of ever-increasing damage to a diseased brain. These moments become markers of the inexorable decline that characterizes Alzheimer's disease.<sup>9</sup>

Families see the project of family caregiving in relation to this medicalized perspective of Alzheimer's as a pathological condition of the brain. The potential of family caregiving—or perceived lack thereof—is measured in relation to its ability to affect the trajectory of Alzheimer's disease, to reverse or even just slow the decline. Both people diagnosed with AD and their family caregivers had difficulty articulating what caregiving comprised and whether they felt they or their spouses were caregivers. To accept one's relationship as caregiving meant ratifying Alzheimer's disease and the effects it had. A reluctance among some family members to call the relationship a caregiving one was made evident as family members talked about “still being” a spouse or debated the question, When did a person become a caregiver? Often, these lines of demarcation were drawn around activities. If family members felt they “really weren't doing much,” then they still talked of themselves in kin terms. But were you helping your spouse dress? Or eat? Or bathe? The more a family caregiver answered yes to these questions, the more they spoke of feeling like a caregiver. Even as they engaged in more that felt like “caregiving,” they still often expressed discontent over their ability to make any substantive change. They talked about doing their best to make their spouse comfortable, to keep them safe, and to love them, but that, in the end, it made little difference.

---

<sup>9</sup> Progressive decline, as discussed below, is one defining DSM criterion for AD and most often comes to characterize the temporal experience of Alzheimer's for those diagnosed and their families.

The despair of doing nothing in the end, a feeling caregivers expressed over and over, emerges within the medicalized context of what Alzheimer's disease is and the ways that family caregiving can possibly affect it. In this milieu, the dominant logic is one of a coming cure. The logic of a coming cure structures a future orientation toward disease and intervention, one which fuels a political economy of hope.<sup>10</sup> It is a logic through which people conceptualize the certain changes as a disease, Alzheimer's disease. It prompts a medicalized relation of intervention and proffers cure as the only viable action a person—whether policymaker, researcher, clinician, family member, or person diagnosed—can take. The catch, however, is that a cure does not exist. Yet, with a particularly evangelical certainty, people insist that, while it does not currently exist, a cure *is* coming...someday. And this insistence that a cure will come, and that care will always be just a stopgap measure, shapes the way families come to understand Alzheimer's disease and their relationship with it. Any understanding of care—what that might mean; what kind of labor, relations, practices, or morality it might involve; what sort of effect it might have and how that effect is measured—comes to be articulated in the public's discourse within the shadow of the coming cure. Against the backdrop, families struggled to live with the day-to-day present of Alzheimer's disease. They found themselves both defined and dismissed within a logic that

---

<sup>10</sup> Mary Jo DelVecchio Good coined the term “political economy of hope” (2001). Writing of the power of the medical imaginary, she wrote: “The medical imaginary, that which energizes medicine and makes it a fun and intriguing enterprise, circulates through professional and popular culture. Clinicians and their patients are subject to “constantly emerging regimes of truth in medical science” (Marcus 1995: 3; Cooke 2001), and those who suffer serious illness become particularly susceptible to hope engendered by the cultural power of the medical imagination” (397). The production and circulation of, the investment in, this hope, then, comes to structure a political economy of hope.

privileged those who might have Alzheimer's someday, invoking those currently living with it as a worst-case imaginary.

### **Medicalization, or From the Clinic Outward**

In the US, the process of coming to understand one's life, at least in part, in terms of Alzheimer's disease and family caregiving can, in many ways, be considered one of medicalization.<sup>11</sup> Medicalization is, most simply put, the process of making something medical. It is understood as a movement outward from the clinic, an expansionary "process whereby more and more of everyday life has come under medical dominion, influence and supervision" (Zola 1983:295). The process is, at its base, a definitional one: "[A] problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or 'treated' with a medical intervention" (Conrad 2007:5).<sup>12</sup> This definitional work often is mundane, an almost imperceptible creep of increased institutional domain.<sup>13</sup>

---

<sup>11</sup> Clarke and her colleagues use biomedicalization to indicate a "second major transformation of American medicine," centering around the increasing biopoliticization and "technoscientificization" of medicine, including the rise of a biopolitical economy, a focus on health optimization, and ever-increasing distribution and consumption of medical knowledge (2010: 1-2). Conrad, who focuses on the definitional processes of medicalization, has written that the shifts Clarke and colleagues point to are "better captured by acknowledging the shifting engines of medicalization and the increasingly market-based forms of medicalization" (2007: 14). Marin Klawaiter, in her work on the biomedicalization and political activism around breast cancer, uses (bio)medicalization to indicate both medicalization and biomedicalization processes at play (2008, 325). In the context of Alzheimer's disease and family caregiving, I have opted to use medicalization as the umbrella term for both processes of medicalization and biomedicalization.

<sup>12</sup> I want to note that the phenomenon under question—event, behavior, physiological or psychological response—must first be called out (by researchers, public health officials, the medical community, the public) as a "problem" to be defined and dealt with.

<sup>13</sup> As Zola writes: "[T]his [medicalization] is not occurring through the political power physicians hold or can influence, but is largely an insidious and often undramatic phenomenon

The production of Alzheimer's disease, from this definitional perspective, is about the medicalization of aging (e.g., Beach 1987; Gubrium 1986; Holstein 1997; Lyman 1989; Lock 2013). Medicalization here concerns a move to recategorize aging processes. The disease category of AD came into being as the body and its aging processes were being refigured in medical terms in an attempt to articulate a distinction between normal and pathological aging. The condition, symptomatically similar to senility, originally was of interest to its namesake psychiatrist because he noted it among younger persons; it was considered *pre-senile dementia*. Later, in the 1970s, a movement in the US to forward a research agenda focused on aging and health coalesced around a consolidated Alzheimer's disease, one which removed the age criterion that had, to that point, distinguished between AD as presenile dementia and senile dementia. Senility in aging was no longer a normal part of aging, but instead a pathological condition.<sup>14</sup>

Family caregivers have long been an integral part of the conversation regarding the production of Alzheimer's disease, as social scientists have recognized their importance to the disease's social construction (e.g., Ballenger 2006; Cohen 1998; Fox 1989; Gubrium 1986). Here, the medicalization is rendered as a problematizing of social deviance that must be controlled (e.g., Conrad and Schneider 1992). "If," as Karen Lyman, who presented one of the earliest articulations of AD as a medicalization of deviance writes, "dementia is viewed only as a

---

accomplished by 'medicalizing' much of daily living, by making medicine and the labels 'healthy' and 'ill' *relevant* to an ever increasing part of human existence." (1972:487).

<sup>14</sup> In the context of Alzheimer's disease, these medicalizing processes have been inherently unstable. In his work, Gubrium described the amount of labor required—on the part of the medical community, advocates, and family caregivers—to find "unity" in the "diverse" presentations of Alzheimer's disease (1986). In her most recent work, Margaret Lock has written that, as much as the biomedical community claims certainty around the hypotheses of Alzheimer's pathological progression, "the ontological status of AD is open to debate" (2013: 22).

biomedical condition, the behavior of the demented person is individualized and power relationships involving the elderly and their caregivers are depoliticized. Thus, the impact of power relationships on illness production and disease is not examined” (602). The behavior to which Lyman refers is most visible among family members within the home, prompting her to write, in an invocation of Foucault, that as “family troubles become medical problems,” “the last wave in the medicalization of family relations is the care of the old, especially those with dementing illnesses” (603). Through interpretations such as Lyman’s, the process of medicalization hinges, in important ways, on a link between Alzheimer disease as medicalized deviance and family caregiving, which becomes a primary justification and technology of medicalization. Caregivers must learn how to “manage” their family member. Caregivers learn strategies to control the behavior of their diagnosed family member, a control that only grows more complete as the person’s condition progresses, resulting in increasingly asymmetrical power dynamics. “Becoming a caregiver,” as sociologist Nancy Blum describes it, is, thus, “less a process of providing care and more a process of managing and ultimately trying to control the family member's behavior. Thus, management strategies, or ways of handling troubles presented by the person with Alzheimer's, give way to processes of social control” (1992: 8). If Alzheimer disease is conceptualized as a loss of self, the medicalization critique posits, the self is lost not through the biological processes of Alzheimer disease but through the social processes of control prompted by a medicalized understanding of the condition as embodied in the brains of those diagnosed with it.

Presenting caregiving in this way, this literature draws a boundary between family members, aligning the family caregiver with the medical community rather than with the

diagnosed person. The result of this has been to understand the person with dementia as medicalized and marginalized, while the family caregiver comes to be seen as, along with those in the medical community, responsible for the marginalization that occurs. Scholars describe Alzheimer's disease as, in Lawrence Cohen's (1998) term, "attributional" in nature, coming into view only as one person notices it as changed behavior in another person, and the family caregiver often has been recognized as one who notices.<sup>15</sup> And, once noticed, once marked as "with Alzheimer's," the person diagnosed becomes subject to the family caregiver's increasing control, a control that continues until the person either dies or is institutionalized. Caught in a "power relationship of caregiving and dependency" (Lyman 1989: 599), the diagnosed person is marginalized, excluded from the relations of daily life often to the point of social death. And the family caregiver is figured as central in this "malignant social psychology" (Kitwood 1997).

What I encountered, however, was more complicated as both a person diagnosed *and* her family members were subject to processes of medicalization. Family caregiving has also arisen through a process of medicalization, a medicalization not just of aging, however, but more specifically of dependency. Alongside the re-emergence of Alzheimer's as a salient disease category, family caregiving also was gaining visibility in the 1970s as family members petitioned alongside researchers and policymakers for awareness of and support for the work they did to take care of people living with Alzheimer's. Without a cure, family caregiving became the

---

<sup>15</sup> In his seminal work on Alzheimer's disease, the production of gerontological knowledge, and the "modern" family in India, Lawrence Cohen described senility as "acutely attributional," which he proceeds to define: "[I]t almost always requires two bodies, a senile body and a second body that recognizes a change in the first" (1998: 33).

medical intervention for AD, one staked out in terms of activities of daily living (ADLs) and described in self-help guidebooks.<sup>16</sup>

Caregiving is recognized as burdensome, challenging, and draining, but since it is so naturalized as a relation among families with illness, rarely is it described as inherently flawed. The assumption becomes that the fault of caregiving lies in the caregiver, in his or her ability to caregive properly. Yet rather than a natural, obligatory relation of families or a learned career, family caregiving is a sociohistorical formation, a set of practices, knowledges, relations, and values that has emerged in the midst of a shifting health care landscape over the latter half of the twentieth century in the US. Family caregiving is the result of the imposition of a health care system, one that originally developed, in part, to wrest authority over health and illness from the family, upon that very institution. The tensions around the morality and practice of caregiving are inherent to what caregiving is, and the structure of caregiving creates challenges that families must learn to accommodate. And, sometimes that accommodation looks like support group conversations about the nearness of death, spousal relations re-figured in parent-child terms, or jokes about silverware.

Certainly there were many moments throughout my fieldwork when a family member would marginalize a diagnosed person through a harsh word, an unnecessary or insensitive action, or even in conversation with others—a quip about plastic forks, for instance. As perhaps the most extreme example of this, family caregivers would discuss hoping for the diagnosed

---

<sup>16</sup> There also is a body of literature in which researchers interested in the way that care work affects a person's health detailed the psychological and physiological "burdens" of that labor have marked family caregiving not only as intervention but also as pathology (e.g., Braithwaite 1992; Liu, Kim, Zarit 2015; Zarit, Orr, Zarit 1985). While this influences what caregiving is and how families experience it, what I am discussing here is something different.

person's death.<sup>17</sup> The analysis of those moments that has dominated sociological and anthropological accounts focuses on the harms of social control: In this brief example, caregivers hoping for physical death can be read as committing the ultimate act of social exclusion. I do not wish to discount these events or the crucial analysis that has been done to recognize the diagnosed person and highlight the harmful, personhood-diminishing effects of her marginalization. In my own work, though, I found explanations of caregiving as social control to be an incomplete explanation for how the lives of families living with AD appeared, for what it meant to be a family caregiver for a diagnosed person. In discussing family caregiving as a process of medicalized social control, researchers—and the policy makers, advocates, and clinicians who draw upon their work—have paid less attention to the conditions under which family caregivers come to feel this way. They have missed the process of *how* a family caregiver might arrive at the place where she hopes her spouse would die. And they have been unable to account for the intensive work family caregivers do to support and maintain their family member *qua* kin and relational substance of the family itself.

### **A Turn to Domestication, or Explaining How Families Understand Alzheimer's and Family Caregiving**

I employ domestication as a means of knowing a phenomenon. At the same time as families living with AD come to understand their family in terms of Alzheimer's disease and caregiving, they also come to understand Alzheimer's disease and caregiving in terms of family, not only their own family history, relations, and narratives, but also more dominant ideologies

---

<sup>17</sup> This is taken up more fully in chapter four.

and understandings of family that circulate in US discourse. The understanding is a hybrid as families make sense of Alzheimer's as a disruption to their daily lives, an interference with their reproductive labor of family-making. A missed belt loop is understood both as a shift in cognitive ability to coordinate dressing one's self and a change in spousal relations as assistance is needed.

Domestication also refers to a mode of enacting Alzheimer's disease and family caregiving. Alzheimer's and family caregiving emerge through the practices and relations of family, and as families *do* them, they also interact with the phenomena of "Alzheimer's disease" and "family caregiving" that circulate through the US imaginary. As families come to understand AD through social and material relations, they act upon those relations as a way to combat what they see as the changes wrought by Alzheimer's. As Alzheimer's disease comes to be located amid forgotten routines, disorienting hallways, or altered intimacies, those become points of intervention. Domestication allows for people, even when conceptualizing of something as medical, to bring other notions and practices to bear upon it.

When, for example, a daughter told me that her father, who was living with early-onset Alzheimer's disease, would not one day walk her down the aisle at her wedding, she was describing a life medicalized, an imagined future re-figured in terms of medical understanding of her father's condition. More, though, she was articulating an understanding of the phenomenon of Alzheimer's disease as one infused with and made visible through the imaginaries, rituals, and relations of kin and family-making. In another moment, as a couple only half-jokingly described Alzheimer's to me as a third member of a *menage a trois*, they gave voice to the way their lives have changed after diagnosis, but they did so through a sexualized metaphor that way reworked the object of Alzheimer's in terms of their relationship and their identification as gay within the

particular historical moment of the 1980s and 90s. Both daughter and couple understood what Alzheimer's *was* not only through biological explanations of amyloid plaque build-up and neuronal death but through their own relations and the reproductive—and regenerative—practices of care and kin in which they engaged to maintain those relations.

### **A Case for a Perspective of Domestication that Builds on Medicalization**

Domestication offers a complementary narrative to the understanding of Alzheimer's disease and family caregiving as medicalizing those who live with them. As a blend of what is considered medical and domestic understandings, domestication encompasses processes of medicalization. A turn to domestication also extends medicalization by forcing a reconceptualization of the assumed boundaries between the medical and the domestic, the possibility of agency for those who are medicalized, and an insistence on a relationality that extends beyond social control.

#### *Dispelling the Boundary Between Medicine and the Home*

Medicalization is a theory of movement: an embodied object of interest (e.g., behavior, action, appearance, biomarker—a “problem” in Conrad's terms) moves out of one domain (e.g., moral, life course, domestic) into the domain of medical understanding and explanation. Scholars also have traced the ways that embodied objects could be *demedicalized*, with homosexuality as the exemplar.<sup>18</sup> Regardless of direction, however, the movement that captivates in medicalization

---

<sup>18</sup> As with homosexuality, the movement between medicalization and demedicalization can be a vacillating one.

is that to or away from the medical domain, an interest that rests upon an understanding that medicine is a social institution and that the history of its rise across the first half of the twentieth century was one of an institutional consolidation of authority and marking of boundaries (Clarke et al. 2009; Starr 1982). Part of this process involved physicians drawing authority over the care of bodies out of the home, minimizing the expertise that family had in care (Abel 2000). As the institution of medicine cohered and gained acceptance, a boundary between the medical and the domestic was produced. While theories of medicalization have moved away from notions of medical imperialism that centered around the figure of authoritative physician (e.g., Ilich 1979), they continue to assert the boundary of the medical institution.

The perspective of domestication, however, unsettles these boundaries as it focuses attention on the range of influences people draw upon as they enact Alzheimer's disease and family caregiving. Enactments of Alzheimer's disease and family caregiving do not presuppose a boundary between the medical and the domestic. Rather, the boundaries emerge through interaction, contingent upon who is involved and what is being done. In this way, domestication, while discussed in this dissertation primarily from the family's perspective, crosses into the clinic, the support group, the laboratory, as well. Whether within family or clinic, Alzheimer's disease and family caregiving emerge as a hybrid of medical and familial understandings of illness and care, contesting the possibility of a clear boundary.

### *Conceptualizing Medicalization as more than Seeking Access*

In a similar vein, critiques of medicalization have rightly rejected the idea that people are passive players in medicalization processes, pointing to the "re-skilling" of a lay public who

sought to engage with an ever more complex biomedical community of not only clinicians, but advocacy groups, support groups, researchers, policymakers, and the media (Williams and Calnan 1996). In an essay entitled “Women and Medicalization: A New Perspective,” Catherine Kohler Riessman asserted that both physicians *and* women actively “have contributed to the redefining of women’s experience into medical categories” and that women did so based on “their own needs and motives” (1983; quoted in Klawaiter 2008: 25). While Riessman documented women’s agency, she was careful to note the “tenuous and fraught” nature of the collaboration, writing that they have “both gained and lost through the process of medicalization.” Riessman was not alone, either; feminist scholars were encountering and writing about women engaging with medical communities in a variety of ways that dispelled any easy notion of imperialistic, paternal clinicians and passive patients (Davis-Floyd 1992; Ehrenreich and English 1978; Rapp 1999; Wertz and Wertz 1977). They showed that, rather than outright rejecting medicalization, women selectively and thoughtfully drew upon medicalized narratives, interactions, processes, and technologies in order to achieve the kinds of care they desired. Moving outside the clinic, scholars have also demonstrated the ways that patient advocates have sought to contest stigma surrounding their condition, to access treatment, and to change policy regarding health care and research (Epstein 1996; Silverman 2011; Klawaiter 2008). Especially amid policy and research discussions, these groups often have acquired scientific and medical expertise in order to be taken seriously. People diagnosed with Alzheimer’s and their family caregivers also have long been engaged in advocacy efforts, pushing not only for more research into treatments, but also to increase supports for family

caregiving (Ballenger 2006; Chaufen et al. 2012; Fox 1989).<sup>19</sup> This advocacy work, too, especially through groups such the Alzheimer's Association, is exemplary of the ways that people will adopt medicalized understandings.

Yet, people living with AD have a more complicated relation with medicalized understandings, as becomes clear from a domestication perspective. Given the lack of medical treatment options, clinical interactions often revolve more around brainstorming shifts in the social and material relations of everyday life than testing and pharmacological intervention. And while diagnosed people and their families are deeply interested in the potential of clinical research, they quickly learn that, within the logic of the coming cure, current research trends are focused on the future population who might come to be diagnosed. So people are invested in access in a different way, one that often focuses on what is possible within the home, on bringing domesticated solutions to bear on medicalized challenges. More, people living with Alzheimer's, both those diagnosed and their families, drew upon medicalized understandings to make sense of and continue their daily projects of family-making.

### *Moving Beyond Social Control to Relationality*

Alzheimer's disease and family caregiving are inherently relational processes, the many dimensions of which become visible with a turn to domestication. Both AD and family caregiving emerge in the spaces of interaction, engagement, and alignment between social and

---

<sup>19</sup> As others have noted, however, the focus of advocacy efforts was quickly consolidated behind research toward a cure. As caregiving was cast within advocacy rhetoric as a burden to be shouldered only until a cure was discovered, it became a necessary evil, costing the nation financially, rather than a legitimate intervention to be supported and funded (see especially Ballenger 2006, chapter 5).

material relations. Further, the manifestation and recognition of what is marked as Alzheimer's amid the social and material relations of person, family, and home; the assumption of family involvement in relations with a medical community, through clinical interactions, support groups, long-term home health or institutional care, and conferences; the obligatory, highly moralized nature of family caregiving; the overwhelming preference for a person to receive care at home: all of these arise from the ways that AD and family caregiving are shot through with ideologies, relations, practices, and engagements of family.<sup>20</sup>

At its center, this dissertation is about the relationship between medicine and family. As such, it draws inspiration from the resurgence in kinship studies. Scholars of this new kinship studies have been concerned with what kinship *is* in a moment where, in the wake of powerful critique against both the biological underpinnings and the Eurocentric assumptions of kinship as an analytic category, anthropologists found themselves unsure as to how to engage with kinship at all (Carsten 2000; Franklin and McKinnon 2001; McKinnon and Cannell 2013). This work has demonstrated the vitality of kinship in everyday life through comparative work on adoption, reproductive technologies, and non-heteronormative family formation (e.g., Carston 2004; Edwards et al. 1999; Thompson 2001; Weston 1991). It also has sought to “follow the trail of kinship relations as they lead...into what are supposed to be the discrete domains of economics, politics, and religion,” asserting the “vitality of kinship relations” (McKinnon and Cannell 2013: 15). Through exploration of these intertwined processes—Alzheimer's disease and family

---

<sup>20</sup> Even in situations where a person does not have family intimately involved in caregiving, which is common in home health or institutional care, the lack of family involvement is marked and called out as morally suspect.

caregiving, medicalization and domestication—I illustrate the inextricability of medicine and kinship, how they are understood, and the effects of those understandings on people’s daily lives.

More than anything, a shift to the perspective of domestication makes it clear that to view the relations between a person diagnosed with Alzheimer’s disease and her family caregiver as a dynamic only of social control is inadequate. The framework of medicalization is compelling in its explanatory power. However, the relational nature of both Alzheimer disease and family caregiving suggest another possibility. As Ingunn Moser writes in her elegant parsing of the many versions of Alzheimer’s disease: “[T]he differences and tensions within medicine presented...suggest that the biomedical version [of Alzheimer’s disease] is not necessarily sovereign. They suggest that it is not necessarily stronger: that it does not necessarily circulate further and come to define what kind of matter of concern Alzheimer’s disease is and what kind of interventions it calls for.” (2008: 103). As social relations, especially family relations, come to the fore, Alzheimer disease is no longer located within an individual’s brain, and family caregiving is more than one individual’s exertion of social control over another. Rather, both emerge within and move through the relations. As they do so, families, who describe themselves as unable to affect the brain’s pathology, are afforded new, relational objects of intervention.

### **Methods: Following Families**

Since 2009, I have been working with people who have been diagnosed with early-onset Alzheimer’s disease, their families, and the medical and professional care communities with whom they interact in order to examine the relationship between Alzheimer’s disease, understood as a disease entity, and family caregiving, as the form of intervention preferred and promoted by

policymakers, the medical community, and families themselves. I sought to understand, from families' perspectives, what it meant to learn to live with Alzheimer's disease both as a person diagnosed and a family caregiver.

Initially, my research centered around the Memory Clinic's support group. The group developed out of a one-day conference held in 2004 specifically for people living with early-onset AD and their families.<sup>21</sup> At that time, families and Memory Clinic staff, who would double the support group's staff, felt that the opportunity to convene beyond a one-time conference would be helpful for people living with early-onset Alzheimer's because their issues were qualitatively different from those living with Alzheimer's later in life (the more recognizable "late-onset" variant). The group's members were primarily diagnosed in the late 40s or early 50s, although there were members who had been diagnosed earlier and later.<sup>22</sup> Time and again during my fieldwork, they and the support group staff would talk about the distinct challenges of living with an Alzheimer's diagnosis earlier in the life course: the financial challenges of being diagnosed before retirement, frequently at what they felt was the height of their career, and the social welfare services afforded to those over 65 years of age; the problems involved in translating services designed for older (i.e., "frail") bodies to meet the needs of people with often more physically robust, middle-aged bodies; the difficulties of maintaining social connections

---

<sup>21</sup> The support group's origin story is that one member had approached the Alzheimer's Association and been told there were no services for people living with early-onset Alzheimer's disease. He and his wife then contacted staff of the Memory Clinic and the Alzheimer's Disease Center with which it was connected, and they organized a one-day conference for people living with early-onset AD. Based on the needs of those who attended the conference, they began convening regularly in the summer of 2004.

<sup>22</sup> One member, who attended before I began fieldwork, had been diagnosed at age 37; I also worked with a person who had been diagnosed at age 63. However, the majority were squarely in what they described as "middle age" or, more frequently, the "prime of their lives."

with extended family and friends as the diagnosed person and his or her spouse fall “out of time” (Hagestad 1996).

I began attending support group meetings in March 2009 as part of the research for my master’s thesis.<sup>23</sup> In addition, I was given access to audio recordings of the breakout sessions that the staff had been making and archiving since shortly after the group began meeting.<sup>24</sup> After my thesis research, I continued volunteering for the group. I attended monthly meetings, helping with the setup before meetings, and sat in on breakout sessions with either family caregivers or those diagnosed. I continued to do so while I designed my dissertation project, meeting occasionally with the group’s director Janis to talk about the project.

When I started my dissertation research, I continued to work with the support group, but also broadened my scope beyond the monthly gatherings. Interested in examining how Alzheimer’s disease and family caregiving emerged in clinical interactions, I began to work in the Memory Clinic, which was connected to an Alzheimer’s Disease Center (the First Alzheimer’s Disease Center (FADC), one of 29 federally-funded research centers in the country at the time), in February 2011. I spent several months observing clinical interactions with patients and their families, including patients’ cognitive testing, case rounds, the daily workings of the clinic and its staff, which included physicians, advanced practices registered nurses (APRNs), an office manager, and a number of research assistants. The physicians—a group comprising primarily neurologists and geriatricians—would conduct diagnostic appointments,

---

<sup>23</sup> For the master’s thesis, I attended two meetings in March and April 2009.

<sup>24</sup> From this support group material and a series of interviews with family caregivers, I produced a thesis on the reorientation of self that family members undergo as they become family caregivers (Seaman 2009).

while the APRNs were responsible for the continuing care of approximately 300 patients annually. Research assistants conducted the cognitive testing, as well as specimen collection and test administration among patients and families in the clinic and the community for ongoing clinical research.

As I worked in the Clinic, I became increasingly curious about the ways that ideas about family—who composes it and what are their relations, what are the obligations of family, what the relationship between family and home, how do families caregive—circulated around the clinic, its materials and spaces, and interactions with and about patients. I discovered that the notions that clinicians and families themselves held about family influenced what it meant to live with Alzheimer’s disease more than any description of changing brain pathology, imaging test, or pharmacological treatment, even within the clinic itself.<sup>25</sup> Family members were written into patient paperwork, assumed in phone conversations when the office manager scheduled appointments, accounted for in the structure of a clinical appointment. A significant portion of the conversation in clinical encounters concerned how the diagnosed person was doing day-to-day, discussed as activities of daily living, and how that daily life affected the person and her family. How is her driving? Is he still working? What is her sleeping like? How does he spend his days? What is her general mood? Has he had any trouble with walking or stairs? Family members, as caregivers, were asked to be both the recorders and reporters of the ways Alzheimer’s disease affected daily life and the intervention for it.

---

<sup>25</sup> This is not to imply that more biomedically flavored understandings of disease and intervention didn’t figure in at all. Certainly they did, especially as pharmacological intervention was used to treat increasing “behavioral symptoms” across the course of a person’s condition. Rather, it is to stress the importance of family and ideologies of family in the clinic.

So much time was spent talking about daily domestic life, I quickly found I had to move outside the clinic to follow families through their daily lives. Between May 2011 and March 2013, I worked closely with seventeen families in which one person had been diagnosed with early-onset Alzheimer disease. I focused on the spousal relationship, as it was the primary caregiving relationship for all the families.<sup>26</sup> I spent time with families in their homes, or at the long-term care facility if a person was living there, at informal gatherings like dinners and holiday celebrations, in medical appointments, and throughout their days, tracing the quotidian practices of life. With two families, I was able to stay for multiple days at a time, following them across the course of those days.

I situated my work with families within a larger context of understandings about Alzheimer's and family caregiving in the United States. I attended trainings for care workers facilitated by the staff of the memory clinic, including a week-long course for long-term care facility memory unit directors. I also attended conferences on both AD and caregiving for clinicians, families, and researchers. Finally, I collected media accounts of AD and family caregiving, including fictional accounts and popular news stories.

## **Plan of the Dissertation**

Across six chapters, I trace how families learn to live with Alzheimer's, what it means to live within the medicalized milieu of Alzheimer's disease in the US, and the ways families

---

<sup>26</sup> Eight families did have teenagers or adult children living with or near them during the time of my research. However, caregiving spouses stressed that they did not want their children to have to be their diagnosed partner's caregiver. While children were not considered primary family caregivers insofar as they were shielded from the daily practices of caregiving, they often provided emotional and material support for the caregiving spouse.

domesticate both AD and family caregiving. “Finding Alzheimer Disease in the Family,” the first chapter following the introduction, is about how and *where* Alzheimer disease—in the midst of uncertainty among the biomedical community about what it is—becomes knowable to the families and clinicians who interact with it. Families begin their narrative of diagnosis with some uncertainty about what a person’s changes mean, yet come to see them as symptomatic of what becomes diagnosed as Alzheimer disease. The changes they discuss, even after the years of clinical engagement, are what might be considered minor events of daily life: lost keys, forgotten eyeglasses, left behind paychecks. Albeit with different motivations for doing so, clinicians and families both come to articulate Alzheimer disease as a visible, recognizable entity within a person’s daily life. The inclusion of families across the diagnostic process speaks to an ideology of family and care that is present within the clinic. Throughout the diagnostic process, clinicians and families together articulate not only the disease, but also the family within which it comes to be located. Chapter two, “‘Alzheimer’s Lives Here’: The Ecological Niche of AD and Caregiving,” asks: After a family leaves the clinic with a diagnosis of Alzheimer disease, what comes home with them? If Alzheimer’s is understood as “living” with a family, what does that mean? Both Alzheimer disease and family caregiving, as sociocultural constructs, usher notions of self, relationality, temporality, and activity into families’ lives, notions that come to structure people’s understandings of what it means to live with AD. As families learn to see Alzheimer’s and family caregiving through these lenses, their relations are altered. Specifically, I argue that AD and family caregiving arose together in an “ecological niche,” a moment in history that places particular moral tensions upon what it means to be a family caregiver in the context of

AD. Through this discussion, the chapter articulates the context in which families come to understand their lives.

Chapters three and four focus on how families come to understand their own lives as under the shadow of a coming cure that is not intended for them. The third chapter, “The Consequence of ‘Doing Nothing,’” is about the inefficacy of the family caregiving enterprise in the context of Alzheimer’s disease. I demonstrate that, as people come to see themselves as a “person with Alzheimer’s” and a “family caregiver,” they understand the value of caregiving in terms of its inability to alter the trajectory of the condition, to change, as it were, the destination of their journey. I argue that this understanding of caregiving’s failure is the product of an activist discourse that privileges the triumphalist narrative of biomedicine’s eventual success: a cure. Given that a biomedical cure for Alzheimer’s disease does not yet exist, this discourse, those who deploy it, and those whose understandings are shaped by it, operate within what I term a logic of a coming cure. The logic structures Alzheimer’s disease as a condition best understood within a series of individual- and population-level trajectories. The possibility of viable interventions subsequently come to be valued in their capacity to enact change upon those trajectories.

Chapter four, “Five More Years: The Temporality of Expectations,” focuses on the competing temporalities of the disease’s trajectory of decline and clinical researcher’s focus on the future. I argue that the pervasive discourse of clinical research, as one of a ‘near future’ always just out of reach but tantalizingly attainable, marginalizes families living with AD in the present. Coming to understand themselves within the strictures of such discourse, families both resign themselves to a ‘present future,’ wherein the conditions of the present extend indefinitely, and struggle to come to terms with an inevitable end. While projects of future negotiation are

hardly unique to these families, the charged stakes in the context of dementia highlight the process, contestation, and implications of anticipating futures. People diagnosed with dementia and their families face a particular dissonance in that, once a diagnosis has been given, their lives are both largely defined by and largely dismissed within biomedical logics. While previous chapters have dealt with the former, examining how families reconfigure themselves in light of a biomedical understanding of their situation, this chapter is concerned with the ways in which biomedical hopes for a dementia cure marginalize those living with the condition. Recent work has brought focus to the production and maintenance of hope in medical contexts. This chapter builds on that discussion by tracing the ways that the construction of a kind of hope on one scale—in this case, a national scale of research and activism—can attenuate a different hope on another, smaller scale—here, that of families.

The final two chapters, then, move to examine how, within these understandings, Alzheimer disease also comes to be domesticated through family relations. In chapter five, “Shifting Intimacies and the Flexibility of Kin Relations,” examines how families draw upon their understandings of kin relations, and the flexibility of those relations, to continue to incorporate a diagnosed person in the daily lives of family. At the chapter’s center, I work through what it means to think of an adult with Alzheimer disease “like a child.” Specifically, I trace how spouses negotiate their shifting relationships across the course of Alzheimer’s. I demonstrate that spousal caregivers come to use their understandings of a different family relationship, that of parent-and-child, to make sense of the changes they are experiencing. Scholars roundly criticize the perception of adults as childlike as dehumanizing; in the context of care and dementia, it is regarded as “infantilization,” that is, “implying that a [person] has the

mentality or capability of a baby or young child” (Kitwood 1993: 542). Yet, I argue that, for families living with AD, conceiving of a spouse like a child can actually maintain and enable processes of humanization, wherein a person can continue to care for and love a person who feels less and less like their spouse.

The final chapter, “Forgetting the House: Making and Unmaking Families through Home,” material relations become the focus of intervention. While the house is a material structure filled with objects of domesticity, for middle-class families in the United States, “home” is the central place of family, marked not only by the kin relations of its inhabitants but also by their shared histories and daily interactions. Over time, houses become homes, producing and produced by families through the accumulation of memory and sociality. This thickening of a familiar web lends the home a sense of intelligibility and routine that makes it feel comfortable and supportive. Homes change constantly, yet despite continual fluctuations of persons, materials, and situations, the home comes to be characterized by its stability, a stability which also is projected onto the family that occupies it. To forget a house, then, threatens to disrupt both material and social relations, to undo both home and family. As the layout and objects of the house become strange to a person diagnosed with AD, so too, family member worry, do the memories, the histories, the lives and familial ties that wend through its rooms and hallways. In the face of AD’s perceived threat to the home, families act to maintain continuity and stability, paradoxically by drawing upon its fluidity. I argue that, feeling unable to change the dementia, they instead make adjustments to the home in an effort to counter this estrangement. They alter rooms and routines, objects and orientations, in an effort to help the person with dementia “remember the house.” In doing so, however, they often accentuate the very unease and

dislocation they seek to resist as modifications become visible markers of the changes wrought both by AD and their interventions. Families therefore work to reconcile the tension between staving off the “forgetting” and changing the house too much, reaching the breaking point of a home’s ability to accommodate change and rupturing its stability permanently.

## **Chapter One: Finding Alzheimer's Disease in the Family**

In May 2011, the First Alzheimer's Disease Center (FADC) hosted a multi-day training for unit directors of long-term care facilities on how to provide care to people with Alzheimer's disease. Amid sessions about human resources management, maintaining nutrition, clinical assessment, and communication, two sessions had been planned around families living with AD—one in which diagnosed persons talked about their experience living with Alzheimer's, and a second with diagnosed people's family members. Intended to give the administrative and clinical attendees a sense of families' experience of living with Alzheimer's disease, the sessions were predicated on an underlying sense that these professionals, despite working with people, many of whom were thought to have Alzheimer's disease, and their families, often did not understand what it was like to live with the condition.

Both sessions began with discussions of the person's diagnosis, and panelists in each worked quickly through the well-trodden narrative ground of what events preceded and ultimately resulted in diagnoses, marking off a series of noticeable changes in the behavior either of themselves or of their family member: forgotten names, plans, or events; lost items; problems at work; social withdrawal; perceptual or functional changes that affected activities such as driving or dressing. In every person's account, the medical diagnostic process itself—the cognitive evaluations, imaging procedures, and physiological testing that went along with it—was narrated almost as an afterthought.

For the session with those diagnosed, Janis O'Connor, a social worker at the FADC and with the Memory Clinic support group for people with early-onset AD, began by addressing the

assembled audience of varyingly attentive unit directors, alluding to the diagnostic challenges of Alzheimer's for both clinicians and families, "As you know...Alzheimer's is a disease that starts gradually. And it can often take a while to figure out what's going on. And *especially* when you're dealing with someone who's younger." She then turned to the panelists, Harold Lawton and Alex Reynolds, two men who attended No Notice and who had done many similar presentations with O'Connor in the past. "So, do you maybe wanna talk about what happened at the very beginning? Did you notice anything was going on or what happened?" Harold spoke first, "I didn't notice that anything was going on, actually." A small man who laughed easily, he did so then, "You know, I was just me. I think it becomes more obvious to people around you before it becomes obvious to you."

Several months later when I would interview Harold with his wife Heidi and their daughter Joelle, the family would flesh out the story of his diagnosis. Heidi told me that she, Joelle, and Harold's co-worker had noticed and begun tracking oddities in his behavior several years before his diagnosis: forgetting to pick up his paycheck, losing his keys, not doing a task "by the most direct route." She told about how once he ordered glasses after an eye exam, but never picked them up; nobody knew until the family received the invoice in the mail six months later. A few times, prodded by Harold's absentmindedness, the couple went through the Alzheimer's Association's "10 warning signs of Alzheimer's" checklist, but "mmm, we kind of concluded, no." The family's general practitioner was, in Heidi's words, "not very attentive to detail" and continued to give Harold's health an annual stamp of approval. His forgetfulness became increasingly apparent, however, and at the urging of a clinician friend, Heidi began to look more seriously into the possibility of dementia. When she told Harold that she thought he

needed to see a neurologist because he might have Alzheimer's, as he told me, "I didn't believe it, but I was willing to go along with it. You want me to get it checked? Okay. You know? That'll objectify it. They did the initial tests and they came back and yes you do have the beginnings of Alzheimer's disease." As she explained their diagnostic process, Heidi told me, "So basically it was our notes—the notes from [his co-worker], from Joelle, and from me, stories, events with Harold, that we went in with." She talked about his scores on the Mini-Mental State Examination, a 30-point measure of cognitive function that is nearly ubiquitously used in evaluation of persons suspected of having or diagnosed with dementia: "August of '08, his score was 29; August of '09, it was 29; August '10 was 28; and September this year was 25." Only the most recent score was considered to be indicative of cognitive difficulties. Yet, despite having scores and imaging test results that pointed to near-perfect cognitive health, Harold Lawton was diagnosed with early-onset Alzheimer's disease in 2007. As Heidi explained, "It was basically on family and worker's observations that he got diagnosed with that."

This chapter is about how and *where* Alzheimer's disease becomes knowable to the families and clinicians who interact with it. The Lawtons begin their narrative of diagnosis with some uncertainty about what Harold's changes mean, but come to see them as symptomatic of what becomes diagnosed as Alzheimer's. By the time we talk, they have a well-articulated narrative of those changes as early indications of a brain pathology they could not see. And yet, despite an understanding of AD as a condition of the brain, the changes the Lawtons discuss, even after the years of clinical engagement, are what might be considered minor events of daily life: lost keys, forgotten eyeglasses, left behind paychecks. How do these daily moments come to be linked to the brain pathology understood as at the heart of Alzheimer's disease?

My argument is that families and clinicians construct the diagnostic links together as they seek, albeit for different reasons, to make Alzheimer's disease a visible, recognizable entity. From families' perspective, the changes a person (or those around him) is noticing are unsettling and intrusive; families seek to understand these changes, most often looking for reassurance through diagnosis that they can be treated. The medical community searches for a different kind of reassurance. Alzheimer's disease, as a disease category, is fraught with uncertainty, and researchers' and clinicians' ability to locate it is undermined by its ambiguity and instability. Diagnosis, for them, asserts that AD is knowable, and it reinscribes their authority over it as a medical condition. Although both parties desire the certainty of diagnosis, there is no fully agreed-upon medical test or biomarker that definitively indicates the presence of AD. In order to construct the chain of evidence necessary for diagnosis, clinicians turn to families as a kind of diagnostic technology that makes Alzheimer's visible in a person's daily life. The inclusion of families across the diagnostic process—in the Lawton's case, as Heidi relates it, family actually provided the bulk of the diagnostic evidence—speaks to an ideology of family and care that is, somewhat surprisingly, present within the clinic. Further, when families come to be calibrated as diagnostic technologies, they are realigned as an entity where Alzheimer's disease is both located and intervened upon.

### **The Trouble with Alzheimer's Disease**

The Lawton family's description of Harold's process toward diagnosis highlights an elusiveness of Alzheimer disease that is felt across families and the biomedical community. The person affected may not see it. Family and friends, even when suspicious, tend to attribute a person's changed behavior to something else. General practitioners are unable to observe its

patterns in their patients. Testing measures, whether questionnaires for the lay public or evaluations run by clinicians, might well miss it. And, since diagnosis, Harold and Heidi have been asked to repeat their story as “training” to long-term care professionals, whose clients ostensibly are living with it at an ever-increasing rate; even ethnographers, who are supposedly becoming expert in its lived contours, don’t really understand Alzheimer’s disease. As Janis told her audience, it is challenging to “figure out what’s going on,” a doubtful evaluation not only of families’ ability to do so, but also of the medical community’s. Moreover, her remark is a commentary on the condition itself: It is hard to figure out what’s going on *because Alzheimer disease is difficult to know*. The ontological grounding of AD is unstable, and what “it” is varies across context. Yet, the stakes of recognizing it, of marking it as known, are high, especially for families and clinicians seeking diagnostic certainty.<sup>1</sup> To diagnose AD as such, they end up turning to each other.

### *A Need to Know*

Families seek diagnosis because they think such a medicalization will bring clarity and understanding. Diagnosis provides a medicalized frame for making sense of changes in a person’s life.<sup>2</sup> In the context of Alzheimer’s disease, these changes often are no more than small disruptions to daily life. For the Lawtons, a diagnosis of AD helped to explain eyeglasses that were never picked up and roundabout approaches to tasks. For Lisa Donnelly, who worked part-

---

<sup>1</sup> Although here the focus is on families and clinicians within the process of diagnosis, many other biomedical and public health parties also are invested in the project of knowing Alzheimer disease—researchers, policy makers, pharmaceutical makers, insurance companies, etc.

<sup>2</sup> Scholars, of course, have noted this across multiple contexts (e.g., Becker 1997, Jutel 2011, Kleinman 1988, Rosenberg 2007).

time as a reference librarian in the local library, she noticed she “just didn’t feel as sharp as [she] used to.” The library director noticed, as well, eventually phoning Lisa’s husband Craig to express her concerns. Others seek explanation for more intrusive events. Shawna Johnson’s husband Jonathan had been increasingly worried that she was having an affair. Although she promised him she wasn’t, he could not shake the idea; he became depressed and frequently was angry at her. As she related at a support group meeting, “He was so mean to me.... I was gonna get divorced. ...He was screaming at me, and he was yelling at me. I can’t do anything, I can’t go anywhere, and I’m like, ... ‘If you continue to do this, we’re gonna get divorced!’ And if we wouldn’t have had the diagnosis, we probably would’ve been divorced. I couldn’t stand it anymore.” After his diagnosis, however, Shawna and Jonathan remained married. Stretched to what she felt was her personal breaking point by Jonathan’s anger and depression, she found the diagnosis medicalized family relations in a way that made them understandable and therefore forgivable. She took it less personally. Jonathan’s anger still existed—she often would talk about his temper towards her and their children—but the link that was made between his anger and Alzheimer’s disease loosened the link that had previously existed between the volatility and his and Shawna’s relationship.

Diagnosis also links the person (who has become patient) to a network of actors, institutions, knowledges, practices, and materials. Given one’s prognosis after diagnosis of increasing cognitive disability, the medical, care, and legal professionals who assist families stress the importance of early diagnosis to enable the person’s involvement in planning for her future (Mace and Rabins 2006[1981]). Within a biomedical paradigm that privileges individual autonomy and choice (Mol 2008), the ideal situation would be one in which a person is able to

partake in her own legal and financial planning, not only for her own future but also for her family's. To ensure the well-being of all, financial and health powers of attorney must be drafted; wishes for care planning should be discussed and documented; advanced directives for end-of-life care, including DNRs (do not resuscitate directives), if one wishes; wills must be written or revisited to accommodate a new vision of a family's future; financial planning must be done to protect a family's assets from the costs of medical care. All of this becomes more difficult as a person's cognitive ability increasingly comes under suspicion, especially from a legal perspective, which privileges mental competence in questions of ability to consent.

Families also seek diagnostic specificity to inform future generations. While the genetics of AD continue to offer most people little prognostic certainty, since early-onset Alzheimer's often can be dominantly inherited, some spouses with whom I worked sought genetic information, and in some cases a posthumous diagnosis through brain autopsy, out of a sense of responsibility for their children.

For clinicians, the epistemological uncertainties of Alzheimer's disease cut close to their professional identity, an identity constructed around accurately reading the body, recognizing pathology, and intervening to alter its course. Clinicians are cognizant of the fact that, although there are diagnostic biomarkers used for research purposes, there is no diagnostic biomarker considered to reliably indicate the presence of Alzheimer's disease for clinical purposes solely on its own grounds.<sup>3</sup> As opposed to clear markers such as elevated blood pressure detected with the

---

<sup>3</sup> As McKhann and colleagues, convened as the National Institute on Aging and the Alzheimer's Association workgroup, write in their recommendations for revising the original diagnostic criteria: "AD dementia is fundamentally a clinical diagnosis. To make a diagnosis of AD dementia with biomarker support, the core clinical diagnosis of AD must first be satisfied. ...[A]ccepted standards for quantitative analysis of AD imaging tests is lacking" (2011: 5).

now-ancient technology of a sphygmomanometer cuff, lowered T-cell counts measured in drawn blood, or masses that become evident under probing fingers or through imaging technology, there is no laboratory test, imaging scan, or known biomarker that will accurately reveal the presence of AD. The lack of a diagnostic biomarker for Alzheimer's disease reminds biomedical clinicians that they still lack understanding regarding the disease's etiology; this inability to definitively locate Alzheimer disease within the materiality of brain pathology lessens clinician's ability to both diagnose and treat the condition.

### *The Distribution of Alzheimer's, or The Roots of the Epistemological Challenge*

The epistemological challenge at the heart of AD diagnosis arises from the intersection of two overlapping issues. The first is that the biomedical community has a great deal of ontological uncertainty about Alzheimer disease—what it *is* remains an unsatisfactorily answered question. Second, continued questions about what AD is open up a space for uncertainty about *where* it is. Specifically, what in the brain can be pointed to as Alzheimer's? And, if a person can't point to a lesion in the brain, then where can she go to put her finger on Alzheimer's?<sup>4</sup> The condition

---

Critiques of the revised criteria found even this tepid acknowledgement of biomarkers' evidence too conclusive. As Lock writes of an op-ed piece by the neuroscience professor Sanjay Pimplikar, "Pimplikar's op-ed, titled 'Alzheimer's Isn't Up to the Tests,' takes strong issue with the notion that the new proposals represent a clear advance in the AD field; above all he expresses concern about the move to systematic use of biomarker detection in order to assist with early diagnoses" (2013: 101).

In my fieldwork, clinicians at the Memory Clinic considered imaging tests as part of the overall evidentiary portrait when they were available and occasionally would request MRIs, primarily for ruling out other possible causes of dementia (e.g., vascular). They rarely called for PET imaging or spinal taps (to measure cerebrospinal fluid) because they were not conclusive and, in the case of PET scans, were rarely covered by health insurance.

<sup>4</sup> Invoking Foucault's *Birth of the Clinic*, Barry Saunders writes of the lesion, "Diseases have been understood through visible, material, sited abnormalities—characteristic *lesions*—since the

fragments; in practice it comes to be distributed across space and time, moved out of the self-evident locus of the brain. Taken together, these issues pose a problem of recognition both for families, who turn to clinicians for the authority to diagnose, and for the clinicians to whom they turn: How does one recognize the changes they are seeing as Alzheimer disease? How can a lived debility or illness be successfully ontologized as a disease?

The uncertain status of Alzheimer disease has a long history (e.g., Beach 1987, Gubrium 1986, Holstein 1997, Lock 2013). Alzheimer, himself, was never fully convinced that the condition was actually a separate disease entity from senile dementia, which was a condition of cognitive change already acknowledged by the medical community. Alzheimer came to recognize what would become his namesake disease—first named such by Emil Kraepelin in 1910 in his influential text *Psychiatrie*—through his work with a fifty-one-year-old woman, Auguste Deter, whom he met during his time as a physician at the Asylum for the Insane and Epileptic in Frankfurt. In his experience, Deter’s condition was an unusual combination of distinct clinical presentation (both her symptoms and a rapid progression), neuropathology, and age of onset. Together, these led Alzheimer to believe that he was “dealing with a peculiar, little known disease process” (Whitehouse et al, Maurer, 21). However, memory loss and paranoia were already understood as part of the clinical progression of senility, even if the progression in

---

early nineteenth century. That was when the ancient imbalances of humors, the sequences of symptoms, the ‘botanical’ constellations of superficial signs were reclassified, in the Paris Clinic, in view of the ‘bright light of the corpse’” (2008: 2, emphasis in original). Later, during a passage on the training of radiologists, he writes of the importance of that first step of location: “What the attending wants is not specification of the disease [at this point in the process] but concise description of a topologic or morphologic situation. *Where is the lesion?* Liquid, solid, gas? Does it contain calcium? How big? Does it enhance? Terms sought here are meant to stabilize a conceptual entity which can then be submitted to more refined diagnostic consideration” (211, emphasis added).

Deter's case was seen as particularly aggressive. Further, both neurofibrils and amyloid plaque had been previously noted in the brains of older persons upon autopsy, although not in the same density as were found in Deter when she was autopsied. The most striking peculiarity in Deter's case was her age: What made the condition unusual was precisely because it occurred in a woman younger than 60, the age which medical authorities had long considered the beginning of the "senile period" (Beach 1987:336). Yet, early onset alone was not decisive, as some patients were older than 60 in other cases that were presented in support of AD as its own entity. Ultimately, whether a person's age made AD a separate entity from senile dementia or simply an extreme presentation of it remained an open debate.

By the end of the twentieth century, the question of age of onset had been dealt with; Alzheimer disease had become synonymous with all previously recognized forms of dementia in older persons (defined in the US as over 65). The change was largely due to the political efforts of activists, researchers, and policy makers in the 1970s who were trying to increase funding for research into the health and illness of people in later life (Fox 1989, Ballenger 2006).<sup>5</sup> The categorical redeployment of the age distinction dramatically increased the reported prevalence of Alzheimer disease and gave a burgeoning movement a coherent enemy. Today, those who are younger than 65 and diagnosed with Alzheimer disease now are diagnosed with an early-onset variant of the condition.

As a disease entity, Alzheimer disease is held together by a perceived link between clinically recognized behavioral changes and Alzheimer's originally noted neuropathological evidence, along with some demonstration that the condition is not part of "normal aging."

---

<sup>5</sup> This history is discussed in more detail in chapter two.

However, a growing body of neuropathology research demonstrates the presence of the neurofibrillary tangles and amyloid plaque buildup within the brains of persons who have not been diagnosed with AD. Increased presence of this pathology correlates with increased age, but not necessarily with the attendant behavioral symptoms of Alzheimer's (see Lock 2013). This not only calls the classical link between symptomatology and pathology into question, it blurs the boundary between the normal and the pathological, this fundamental "threshold of discontinuity" (Post 2000: 248), almost beyond any possible distinction. Margaret Lock has detailed the challenges the biomedical community has encountered as they have attempted to identify a coherent entity of Alzheimer disease and make it distinguishable from the inevitable processes of aging (2013). As she writes, "[I]n the first decade of the 21st century emerging research, largely resulting from epidemiological population-based data, has shown repeatedly that the question of what exactly constitutes AD, and who might be at risk for it, remains unanswered. These findings tip the scales toward an argument for the inextricable entanglement of dementia with aging" (47). As the significance of Alzheimer's pathological gold standards are questioned, the medical community's ability to point at a specific part of the brain, a particular fleshy abnormality, as Alzheimer disease is disrupted. If to know a medical condition is to fix the expected range of its pathological expression—what causes it, how it progresses, where and how it will end—when it comes to AD, much of the diagnostic pathology nevertheless remains opaque to biomedicine.<sup>6</sup> The epistemological challenge of treating Alzheimer disease, then, is underscored by the ontological uncertainty of knowing what Alzheimer's disease is. While few seem to question that

---

<sup>6</sup> The exception, of course, is the certainty of its temporality, its progression and endpoint, a subject that will be discussed in detail in Chapters 2 and 4.

Alzheimer's disease is a thing, what that thing is, what parts compose its whole, remains less certain. And if the line between disease and "normal aging" is unclear, if the expected pathology is not predictive, if what Alzheimer's disease *is* remains up for grabs, there is little from which to hang a diagnosis of Alzheimer's disease (which, after all, is a way of labeling something as known consistent with the medicalization process seen in the family stories above).

Along with a growing uncertainty about the coherence of Alzheimer disease (or, alternatively, one might say a growing certainty about its lack of coherence), a second issue concerns the unruly distribution of AD. As science studies scholars have demonstrated, objects are heterogeneous and distributed (e.g., Berg and Mol 1998, Law and Singleton 2005, Mol 2002); what an object is depends upon the context in which one's knowledge of it is situated (Haraway 1988). Annemarie Mol (2002) has marked the distribution of arteriosclerosis across the different spaces of a hospital and the people who occupy them, articulating how, as the condition is multiply conceptualized, so is the body in which it is found. The condition that comes to be marked as Alzheimer disease is no different. As the ontological character of AD shifts, depending on the stance of the viewer, it moves fluidly across the borders of the "body proper" into spheres of practice—from the brain to other systems of the body affected by exercise or diet, social relations, population statistics, and back again (Farquhar and Lock 2007).

Insofar as Alzheimer disease is differently figured across varied contexts and actors, it also is distributed across a "single" case. As much as the condition is strangled neurons, brain atrophy, and amyloid plaque buildup in a person's brain, it also is his missed answers on the cognitive testing conducted during a clinic visit, the names he forgot at a business meeting, and his recent lack of conversation over dinner, so out of character for his normally talkative self. It

spans clinic, office, community, and home, appearing slightly different in each as one AD patient moves across these spaces.

Not only is Alzheimer disease spread across space, it also is distributed across time. Alzheimer disease, as a condition of the present, only comes into being through its problematic connections to the past and the future. Memory loss is, of course, the overriding symptom associated with Alzheimer disease. Of the conditions that must be met for a diagnosis of AD according to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV, 2000), memory loss must be one. Loss of memory indicates a disconnection from what is commonly perceived as the continuous flow of temporality—a person is both disconnected from their past, as she is rendered unable to access it, and from the future, as her present can no longer be reliably located as a memory for a future use.<sup>7</sup> Her future is further implicated by the uncertainty of the diagnostic process. An absolutely definitive diagnosis of AD can only be given posthumously, with a brain autopsy that reveals the location and amount of AD pathology. A possible or probable diagnosis of the condition is all that can be conferred in the present, a promissory note for full diagnostic medicalization in the future.

### *The Problem of AD as a Problem of Evidence and the Family as Diagnostic Technology*

The process of diagnosis is, in many ways, the constitution of a single case of disease. It is what Rosenberg has called “an indispensable point of articulation between the general and the particular” (2007: 16). Once articulated, specific elements—noticed changes, a language of

---

<sup>7</sup> This is different from Young’s (1995) description of PTSD as a condition of time and memory, where he describes the continual, intrusive folding of the past into the present through the eruptions of traumatic memory.

symptomatology, traces of pathology, and a disease category—are arranged in a series of indexical links. That is, a perceived change within a person comes to index the presentation of symptoms, which indexes an underlying pathology. This chain, properly arranged, acts as an indexical icon of the disease itself. The inverse of this indexical chain, then, is understood within biomedicine as the causal process: a condition is the result of pathological processes that produce certain symptoms, which become visible through certain changes. This understanding of etiology and presentation of disease, and the ability to reconstruct it in reverse through the diagnostic process, is what solidifies much of the explanatory and authorizing power of medicine and its practitioners. If the act of diagnosis is successful, it ties a particular person’s symptoms to a disease category and, in the process, pulls the distributed elements into one location: a person’s body, her brain.<sup>8</sup>

In the context of Alzheimer disease, this process cannot often be entirely successful, and the instantiations of Alzheimer’s disease are fractured, distributed across space. Similar to other chronic conditions in which the biomedical community is still uncertain about the complexities of the pathological mechanism(s), the indexical construction of AD falters at the link to underlying pathology. Without a pathological ground, the abstract disease category, the clinically-induced presentation of cognitive difficulties, and the moments of daily life become more difficult to tie together. They remain spread across body, clinic, home, and community.

---

<sup>8</sup> Moriera (2010): “I conceptualise *individualisation practices* as condensing 'memory loss', through a variety of representations, diagnostic classifications and techniques, into the individual's own body and thoughts and, in turn, making the individual's self correspond to the operations s/he can perform on her/his memory.” (120)

In the clinic, however, the lack of a firm pathological ground is not noted as an issue in the diagnostic process. During my fieldwork, I never heard a clinician say anything akin to, “Diagnosing Alzheimer disease is difficult because we’re not sure what it is.” As noted above, however, what I did hear, and often, was a lamentation about the lack of reliable biomarkers for clinical use. The diagnostic weak link discussed by clinicians and researchers was the evidence. Does a buildup of beta amyloid plaques visible through a PET scan count? What about an elevated level of tau protein in cerebrospinal fluid or a loss of brain mass as seen on an MRI scan? After all, a posthumous diagnosis of AD through brain autopsy should exhibit signs of neuritic amyloid plaques, neurofibrillary tangles, and brain atrophy. These are all tests a clinician might want to do as part of a clinical examination, yet none is considered a diagnostic biomarker in and of itself, especially as people who are not considered to have Alzheimer’s disease can have one or more of these indications of pathology.

Biomarkers in other diseases make compelling evidence (e.g., HIV/AIDS, rheumatoid arthritis, cardiovascular disease). Dr. Edwards, one of my informants from the Memory Clinic, talked about the difficulty of an Alzheimer disease diagnosis as partially because “it’s one of those diseases where we don’t have a blood test or an imaging study that gives us the diagnosis.” His word choice, though likely causal, is telling: A blood test or imaging study would “give” the diagnosis. Biomarkers have the appearance of authorizing objectivity: When they can be relied upon, they are irrefutable evidence of a condition, and the clinician becomes the messenger of their meaning. By understanding the diagnostic process as the constitution of indexical chains, it becomes clear that the evidentiary power of biomarkers comes, in part, from their especially

proper embodiment. With both the sign of the biomarker and the causal pathology located in the body, the distance that must be covered along the indexical is reduced.<sup>9</sup>

Unable to rely upon a biomarker, a diagnosis of dementia remains, as it was described in a 1984 report announcing the still-dominant criteria for diagnosis of Alzheimer's disease, "a diagnosis based on behavior" (McKhann et al. 1984: 940).<sup>10</sup> A diagnosis of dementia indicates the presence of a constellation of symptoms that come to be pinpointed through the clinical process as cognitive difficulties; one is always memory loss, and others might include visuospatial difficulties, issues with finding words or recognizing objects, problems with motor functioning, or challenges with processes like making decisions, thinking abstractly, or following multiple directions, what is referred to as executive functioning. The diagnostic challenge becomes a problem of wrangling into the clinic the far-flung moments when and where AD

---

<sup>9</sup> Ludwig Fleck, in his work on the development of medical understanding of syphilis (1935), follows the trails of a similar diagnostic mystery. As he demonstrates, the development of the Wassermann test was directly related to how syphilis was conceived.

<sup>10</sup> In 1984, a work group was convened by the National Institute of Neurologic and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) to identify a set of clinical criteria for determining Alzheimer's disease. Disease criteria, revised in recent years (McKhann et al. 2011), have evolved to include recognition of a "pre dementia" classification of mild cognitive impairment (MCI); the limited inclusion of biomarkers as part of the diagnostic process; genetic components of AD, especially among those with the early-onset autosomal dominant form of the condition; and the heterogeneity of pathology underlying dementia, including "Dementia with Lewy bodies, vascular dementia, behavioral variant frontotemporal dementia, and primary progressive aphasia" (264). Despite this, the clinical criteria remain dominant. The authors delineate between "AD dementia," as "the clinical syndrome that arises as a consequence of the AD pathophysiological process," provide "core clinical criteria" for all-cause dementia, probable AD dementia, and possible AD dementia, and ultimately discuss "AD dementia with evidence of the AD pathophysiological process." As they write, "The diagnosis of pathophysiologically proved AD dementia would apply if the patient meets the clinical and cognitive criteria for AD dementia outlined earlier in the text, and the neuropathological examination, using widely accepted criteria, demonstrates the presence of the AD pathology" (268).

becomes visible in a person's life, such that they can be tied to a person's grey matter. A clinician must mark the condition of AD within a person's daily routine, her social relations, her ability to act upon the things in her house, her performance at work, and her narratives of her past in order to be able to mark it—diagnose it—as located in her brain.<sup>11</sup>

In order to understand how Alzheimer's must be expressed amid a person's daily life, clinicians turn to the family. The family is a domain where an understanding of Alzheimer disease is by now well articulated by experts. A large body of research has focused on the condition's effects on a family's daily routines, their social relations, financial stability, and the health of non-diagnosed family members; this research has given clinicians a sense of certainty about what Alzheimer disease *is* within the family, even as they remain uncertain of it within the brain. Moreover, as argued above, families provide the particular evidence of AD as it is distributed outside the clinic, which clinicians then are able to link to the general disease category.

In this way, the family acts as a form of diagnostic technology, albeit one that must be calibrated and weighed somewhat idiosyncratically. Consider Dr. Edwards' words, as I asked him about the reliability of patient and family narrators: "So you have to really tease out the self-reported information from not only the person experiencing the symptoms, but then an informant, you know, somebody who knows them. ::And what I've come to realize over time is that, um:: the story's always--the true story's always somewhere in between the range of what the family's telling me and what the person is telling me. ...And, again, I'm taking my priming and

---

<sup>11</sup> As discussed below, this process of individualization, a challenge in many ways common to any diagnosis, is made more challenging in the context of Alzheimer's because the person is rendered unreliable just by the fact of their entering a memory clinic as patient.

my motivations into account. So you've got three people in the room who have slightly different stories, and the true story's going to be somewhere in between.” He spoke of the clinician as “a non-fictional author. You're really trying to listen to the stories from both sides, trying to figure out what that pattern is, and putting it down in writing.” As he discussed the development of the “story,” he continued:

[Y]ou're trying to do your best. You try to share with the family so they get a chance to review it. Or the person. To make some decision points as far as if I got the story somewhat right. And then you use time. And sometimes that's what I have to use. So I can make my best story for now, but then...if I can follow people or I can get them to come back a year later, I can see if, which parts of the story are fitting or not. And so we use time, we use interview with multiple people to try to get us the best opinion. And then our pen-and-paper tests that we do in neuropsych[ological testing] to give us some input. And try to weigh and balance that into what might be the most logical fit.

As he describes it, the form of the diagnostic process for Alzheimer’s disease as the construction of a story is hardly unique: It is a “ritual of disclosure,” through which “a curtain is pulled aside, and uncertainty is replaced—for better or worse—by a structured narrative” (Rosenberg 2007:32; see also Buchbinder 2015; Kleinman 1988; Mattingly 1998; Mattingly and Garro 2000). The diagnosis, when it is felt to be accurate, reflects the “true story” of the information that emerges through the clinical process, consolidating it into the most (patho)logical fit and making the disease clearly visible. Yet, for AD, the technologies for making that diagnosis become other stories, those of the patient and his or her family. Recall the Lawtons: Heidi went so far as to suggest that the observations she and others compiled were *the* evidence that led to diagnosis, even in the face of neuropsychological testing that might have indicated otherwise.<sup>12</sup>

---

<sup>12</sup> The certainty of evidentiality that Dr. Edwards attributes other forms of information as diagnostic technologies does not extend to the kinds of information elicited in the clinical process of diagnosis for dementia, a fact that does not go unnoticed. In each case, as he says, he

## **Families Making Alzheimer's Disease**

To act as a diagnostic technology, families must be calibrated to see Alzheimer disease amid the workings of their daily lives. As they are calibrated—working through diagnosis, follow-up clinic visits, support group meetings, and daily interactions—they help to pull AD together as a condition, reducing the scatter of its distribution and making it visible for marking, measuring, tracking, and treating. In the process, family members are realigned: They become a different family as the material and social relations of their lives shift to account for the presence of Alzheimer disease in their midst.

Calibration is an iterative process of testing and adjustment intended to increase the reliability of an instrument's measurement ability. In his work on the epistemology of experimentation, philosopher of science Allan Franklin has defined calibration as “the use of a surrogate signal to standardize an instrument,” where “surrogate signal” refers to a known result against which the unknown measurement results of an instrument is tested (Franklin 1997:31). As he writes, “If an apparatus reproduces known phenomena, then we legitimately strengthen our belief that the apparatus is working properly and that the experimental results produced with that apparatus are reliable” (Franklin 1997, 31). A thermometer, for example, that reads the previously known temperature of an object (the surrogate signal) as the same would be

---

must depend upon “slightly different stories” from each person (and sometimes from the neuropsychological testing, as well), searching out a diagnosis that remains “somewhere in between.” With these diagnostic technologies in hand, as he describes it, he must become the “author,” the one whose authority legitimizes a diagnosis; he is forced to elicit the diagnosis from a variety of imperfect and unreliable information, which he organizes, weighs, and balances. Invoking the oft made distinction between science and art, he referred to this authoring as “part of the art,” stressing that “it's not perfect. It's definitely not a perfect art.”

considered reliable and ready for use in experiments where an unknown temperature were to be measured. Soler et al. (2013) have proposed a conceptual framework for calibration and its uses, in which they described a primary aim of calibration as the “mastering” of the discrepancy between the measurement actually obtained with an instrument and the imagined optimally achievable measurement (286-8). In their framework, the process of mastering is an iterative one, involving two steps: the evaluation of the discrepancy, and if necessary, its correction.

In addition to the routine calibration of a number of what Soler et al. call “material instrumental devices” (e.g., spectrometer, thermometer, electron microscope, gravity-wave detector; 2013: 268), some science studies scholars have extended the use of calibration to other kinds of measurement and assessment objects (see Soler for a full review). Here, the pertinent work involves the calibration of people. When people, as measurement instruments, are calibrated, the surrogate signals most often discussed are other people. Andersen (2013), for example, has written about the calibration of trust among lay and expert communities, who are “epistemically dependent” on each other for knowledge they have not personally tested. In these instances, the person seeking reliable knowledge must evaluate the other’s trustworthiness, and she does so by comparing the trustworthiness of the unknown against that of people she already deems trustworthy. If she has expertise in the knowledge domain, she can evaluate the other’s trustworthiness in comparison to herself and her own knowledge. If not, she must evaluate other indicators, such as “argumentative superiority, agreement from additional experts, appraisal by meta-experts, evidence of possible conflicts of interest or similar forms of bias, and past track records” (Andersen 164). These sources provide her the data points of measurement to evaluate the trustworthiness (or, in the case of Andersen’s work, *un*trustworthiness) of the person and the

quality of their epistemic and moral character, and thus determine whether the knowledge produced by that person's work or research is useful and dependable.

Calibrating family members as caregivers and people with Alzheimer disease has some formal similarities, especially in the way families accounts are evaluated against those of other people. Clinicians evaluate caregivers, in part, against a repository of their own collected knowledge of caregivers, as well as against an abstracted imaginary of the ideal caregiver. People with Alzheimer's are evaluated against both the clinician's experience of other persons diagnosed with AD and their understanding of the functional disease category. However, the calibration process also is different from that reviewed by Soler and colleagues because family members are being evaluated *as they become* caregivers and people with AD; they are being constructed through the process of calibration. Unlike evaluations of instrumental trustworthiness, where little subsequent work is done to alter those evaluated, the step of calibration is corrective and pedagogical with family members, precisely because they are not yet "family caregivers" and "people with AD." In this way, the calibration of family members through the diagnostic encounter is a process of becoming, a kind of ontological choreography (Thompson 2005)<sup>13</sup> that draws people and disease category into a specific alignment.

---

<sup>13</sup> As Charis Thompson writes of ontological choreography in her work on how "parents" are made through the processes of artificial reproductive technologies (ART) clinics, "The term *ontological choreography* refers to the dynamic coordination of the technical, scientific, kinship, gender, emotional, legal, political, and financial aspects of ART clinics. What might appear to be an undifferentiated hybrid mess is actually a deftly balanced coming together of things that are generally considered parts of different ontological orders (part of nature, part of the self, part of society. These elements have to be coordinated in highly staged ways so as to get on with the task at hand: producing parents, children, and everything that is needed for their recognition as such" (2005: 8).

### *Calibration and the Caregiving Family*

When families enter the clinic they have a prior history, relationships, routines, and shared familial spaces. As they become a sort of diagnostic technology, they add to this background the emergent roles of “family caregiver” and “person with AD.” In doing so, family relations are realigned. Though they are not built from the ground up, families nevertheless undergo a specifying process of realignment, refiguring the materials an existing family—the strength of relations, the teeth of obligations, the routines of daily life, the space of home—into new formulations. As families are realigned, they tend to draw closer to contemporary medical, legal, political, and social understandings of Alzheimer’s disease and the family’s capacity to attend to it that compose the imaginary of a caregiving family. The project of realignment, then, is not to create families anew, cut whole from the cloth of clinical expectations and needs, but to rework the existing family into a series of relations that are recognizably those of caregiving. While such a project most frequently occurs over an extended period of time, it begins, in many ways, during the process of diagnosis. In the process, clinicians and families together bring Alzheimer’s disease into the light, making it visible within the contours of a particular family.

The bureaucratic arrangements of clinical interaction make it clear that, even before a patient enters the Memory Clinic, there is an assumption of family involvement. Within the Clinic, the space for clinical interactions is divided between two “Family Rooms” and two “Examination Rooms;” and it quickly becomes apparent that one is no less examination space than the other.<sup>14</sup> Evidence of the expectations of families sits in cabinets under the office

---

<sup>14</sup> While the designation of one room specifically as the “Family Room” is relatively unusual in clinics, the movement of the person being examined, the accompanying family members, and clinicians across multiple examination spaces in the course of an appointment is common.

manager's desk. The caregiver's guide, pre-appointment paperwork packets, and a number of resource materials specifically for and about family—pages on communicating with a person with Alzheimer's disease or working with challenging behaviors, caregiver community resource guides—can be found nestled in file folders amid more obviously medical materials about types of Alzheimer's disease or medications used to treat its symptoms. Patient files also contain the family between their pages as “medical history,” as letters written by the clinician providing diagnosis or follow-up treatment after every visit, as handwritten notes about calls a person's family has made to clinicians with questions or concerns about behavior, medication, or their own physical and emotional difficulties.<sup>15</sup> In all these spaces and materials, the imagined family sits side-by-side with Alzheimer's disease, its symptoms, and its treatment; as the families come into the clinic for an initial visit, the two are set into intertwining motion, and the process of realignment begins.

Upon calling the Memory Clinic to request an appointment, a person will be asked by Christine, the office manager, if he is the patient, and if not, what his relationship is to the patient. Together, the questions suggest that the elsewhere idealized autonomous patient is not the expected attendee of the memory clinic; if it were, the questions would not be part of the standard appointment scheduling interview. The distinction marks a relation that is already seen in terms of dependency, one that becomes even clearer in the small packet of patient information paperwork that Christine mails out to be completed before the appointment. Within the packet, two forms, the Patient Administrative Form and the Review of Systems and Medical History, are

---

<sup>15</sup> During my time at the Memory Clinic, paper files were in the process of being replaced by electronic medical records. However, the process was not complete by the time that portion of my fieldwork ended, and the paper files remained in the office.

especially explicit about the distinction between the patient and the person responsible for coordinating and managing the medical interaction, and these forms start to flesh out the nature of each person's position within their newly aligned family relations even before they enter the clinic.<sup>16</sup>

The first, the Patient Administrative Form, describes the patient, in the process casting the family member as an informant necessary to provide basic contact and demographic information about the patient, as well as emergency and medical contacts. At the top of the form, just below the memory clinic's name and form title, is a space for "Name of person filling out this form." Only after this elicitation is there a section entitled *Patient Information*, requesting the patient's name, address, gender, and phone number. Farther down the page, the *Informant's* information is requested as the primary emergency contact. The possible kin ties of the informant are presumed here in a series of checkboxes: "Please specify relationship with the patient: Spouse, Son/Daughter (including stepchildren), Son-in-law/Daughter-in-law, Grandchild, Parent, Brother/Sister, Other." Already the person and his family are being realigned as a "caregiving family." As the Patient Administrative Form's language concretizes the distinction between the author and the object of care, the documentation, and by extension the clinic staff who utilize it, adjust relations between family members, highlighting them as dependencies that may or may not have existed previously. People, even before a first visit to the clinic, and very often before diagnosis, are assumed within the administrative processes of the clinic to be dependent upon

---

<sup>16</sup> The patient information packet that the clinic sends out contains seven forms, including paperwork on the patient and her medical history; a referral form and a form authorizing the release of medical information from other institutions (e.g., lab reports, results from imaging tests, and provider notes); forms to authorize billing and payment, as well as information about how to secure assistance with medical costs; and a notice of the memory clinic's privacy policy.

another to the point that they are not making their own medical appointments. In addition to reconfigured family relations, the realignment process also produces new relations with clinic staff. With the solitary patient marked as the occasional exception, the unmarked, normalized relationship within the memory clinic comes to be between clinic staff and the family, a caregiving family.<sup>17</sup>

The Review of Systems and Medical History form, a six-page document designed to elicit a person's medical history, shifts the family member to a medical informant. The form is broken into multiple sections. Some, such as Medical and Surgical History, seem as though they would be standard to any requested medical history, as the form asks the person filling it out to "Please explain any current or past problems or surgeries" related to, for example, lungs, cancer, hypertension or weight problems. These sections contain little reference as to whom the person filling them out might be, one simply a checklist of categories (e.g., Endocrine) and symptoms (e.g., Cold intolerance, Heat intolerance, Frequent urination, Excessive thirst). These sections utilize the language of a molecularizing medical register, targeting bodily systems and focused symptoms, and there is no mention of a patient.

When the possibility of Alzheimer disease is made visible in the questions, however, the form shifts in its focus from physiological systems to people, and the relations between them. "The patient" appears, as does the difference between this patient and the person who serves as

---

<sup>17</sup> Although the literature frequently is pointed in its inclusion of friends as possible caregivers, friends, in my fieldwork experience, were rarely intimately involved in a person's care. No one I worked with had a friend as their primary caregiver, and at the Memory Clinic, friends never made the initial call to the clinic, completed the paperwork, or attended the initial appointments during my observation. For some families, friends *did* provide support to the primary caregiver, and occasionally a friend would attend the Memory Clinic support group. However, the experience of many was an isolation from friend networks across their time living with dementia.

her informant. Sections on Family History and Medications, which also would appear on any standard medical history, ask additional questions such as: “Are there first-degree family members of the patient (parent, sibling, child) with a history of: Alzheimer's disease, senility, or hardening of the arteries, or some other memory problem?” and “Has the patient ever taken a medication for his/her memory?” In these questions, information is requested about “the patient,” rather than “you,” “your family,” or “your memory.” The third person is used almost exclusively throughout the form; “you” is used in four questions. While two of these appear flexible enough to possibly reference the patient (“What was the FIRST problem that you noticed?” and “Have you conducted legal planning?”), the others more rigidly articulate the distinction: “Do you think the patient feels guilty about the way his/her life has turned out?” and “Do you feel that he/she is driving safely?<sup>18</sup>” The “you” of these questions is, once again, the informant family member, who no longer is being called upon to provide information like patient’s name, age, and address but rather about moments of memory loss, possibilities of dysphoric affect, and the ability to complete daily tasks. Both the person with possible AD and the potential family caregiver are implicated; and the relation between them is being adjusted as the person with Alzheimer disease becomes the one who exhibits these kinds of symptoms, and the family caregiver becomes the subject, the one who is already becoming more attuned to seeing them.

---

<sup>18</sup> A series of questions are designed to determine if the patient is experiencing depression. Often, because of a similar symptom presentation (e.g., social withdrawal, increased confusion), people who are eventually diagnosed with dementia are initially diagnosed with depression. This is especially common among people with early-onset dementia diagnoses, as dementia is not the initial expectation of a clinician. In addition, people with diagnoses of dementia are also co-diagnosed with depression.

In his review of the literature on and anthropological attention to the role of documents in bureaucracy, Matthew Hull (2012) writes that documents are more than “simply instruments of bureaucratic organizations.” He stresses their generative role as “constitutive of bureaucratic rules, ideologies, knowledge, practices, subjectivities, objects, outcomes, and even the organizations themselves” (253). The Patient Administrative Form and Review of Systems and Medical History form both function to constitute a series of new relations around the possibility of disease that is being entertained. Explicitly, they sketch a symptomatology of Alzheimer disease. As the forms are completed by the family, members begin to see the condition nestled in the moments of their lives perhaps for the first time. A link is forged between the clinically known condition and a person, between the general disease category and a particular instantiation of it.<sup>19</sup> Along with this, a family member (or members) becomes visible as record keeper. Calibration has started: *You thought that was depression, but Alzheimer disease often can look like depression, especially in its early stages. Keep watch. Be accurate.* In addition, a relation with the clinician has already begun, the documentation enacting and naturalizing her expertise as it begins to order the family’s experience. This process only continues as the family enters the clinic.

---

<sup>19</sup> As Hull also writes, documents work to specify: “The constructive capacities of discourse have long been recognized, but what difference to processes of construction does it make when discourse and other activities are mediated by documents? Discursive logics, concepts, norms, and social relationships can account for classification schemes, the criteria for bureaucratic determinations of what sort of person or thing fits within them. But documents are what mediate between these schemes of classification and particular people, places, and things, constructing *this* person as a victim or *this* house as an encroachment—or even *this* as a house. Documents are central to how bureaucratic objects are enacted in practice” (2012: 259).

*Pulling Alzheimer Disease Together and Placing It in Everyday Life*

In a person's initial visit to the Memory Clinic, the primary objective, from the perspective of both clinicians and family members, is to arrive at a diagnosis.<sup>20</sup> In order to do so, they must pull distributed information together such that it can be ordered into the indexical chain of elements recognizable as a single instance of Alzheimer disease embodied within an individual. A variety of diagnostic mechanisms are utilized in the process. Many of these, such as a neurological examination or blood tests, are exclusionary in nature; they are intended to indicate if behaviors or changes thought to possibly be Alzheimer's are perhaps caused by another condition, such as stroke, Parkinsons' disease, or other dementias, some of which might be reversible or more treatable. The two primary mechanisms used to elicit instances of symptom presentation that would indicate Alzheimer's disease are the neuropsychological evaluation and the collection of a medical history.<sup>21</sup>

---

<sup>20</sup> While the process of diagnosis can span multiple clinic visits, one goal of the Memory Clinic, according to Dr. Edwards, is to provide diagnosis within a single visit.

<sup>21</sup> In Margaret Lock's work, she discusses the diagnosis being described as a "wastebasket," what remains after all other possibilities are "thrown away." One neurologist, countering this description by complicating the "purity" of Alzheimer's disease as a diagnosis, outlined it as follows:

"What I would say is that historically, Alzheimer disease was truly a wastebasket. So if you go back a few decades, Alzheimer disease in the textbooks was a diagnosis of exclusion. You would take somebody with dementia, and you would say, they don't have this, they don't have that, they don't have the other thing, and therefore they must have Alzheimer disease. But, significantly, the wastebasket didn't have all the Alzheimer disease in it because—well, strokes don't prevent you from getting Alzheimer disease. So if you throw out your strokes, okay, very many of those people have Alzheimer disease, but are missed. And if B12 deficiency and hyperthyroidism are thrown out, you often throw out AD as well" (2013: 55).

He goes on:

"So this wastebasket was a mess. And so what's happened over the years with the recognition of mixed dementias is the change from a diagnosis of exclusion to a diagnosis of inclusion.

"[T]oday, when we train people, they learn that Alzheimer disease coexists with other common diseases. And these diseases probably actually contribute to dementia and make it *more* likely.

The former works most forcefully on the patient herself, attempting to forge a convincingly individualized and internalized link between the person and the Alzheimer's disease, such that he becomes a "person *with* Alzheimer's disease." Clinicians attempt to have a patient produce symptoms that would indicate Alzheimer's disease through the administration of the neuropsychological evaluation, a series of tests designed to expose certain kinds of cognitive weakness. At the Memory Clinic, as with most specialized memory clinics, the evaluation began with the Mini Mental Status Examination (MMSE), an 11-question test designed to quickly evaluate the cognitive abilities of patients (Folstein, Robins, and Helzer 1983). The questions evaluate cognitive capacity along four dimensions: orientation (Does the person know what day, month, season, year it is? Do they know the state, county, city, building, floor where they are?), registration and recall (Can the person repeat a given series of words, now and after a short time?), attention and calculation (Can the person complete a task that demands continued attention, such as counting or spelling backwards?), and language (Can the person follow a series of directions, write a complete sentence, and draw an object?). If the patient scored fairly highly on the MMSE, a likely occurrence during diagnostic visits, a research assistant would administer a battery of more in-depth cognitive tests. These last approximately an hour, testing skills such as ability to recall details of a story, recognition of patterns, word recall, and spontaneously naming items of a category (e.g., animals), and the research assistant enters answers into a computer as

---

We train people to ask themselves, does the person have the characteristic temporal and spatial pattern of a cognitive deficit? And so if you have somebody who moves from a progressive amnesia [memory loss], to profound amnesia, followed by problems of orientation and so on, I mean that's a pattern that's just so unmistakable, that 90 plus percent— there are some things that can mimic it, but there's a pattern that 90 percent plus most of the time—these people have Alzheimer disease" (56).

the patient provides them. Upon completion, the assistant collects the computed results of an algorithm that determines whether a person has possible, mild, moderate, or severe impairment across five domains: orientation, memory, attention, language, and perception. Together, a person's results on these tests can indicate a diagnosis of Alzheimer's disease, and in doing so, bind person and AD closer together.

The elicitation of a medical history works primarily on family members, as the process of calibration attunes them to the evidence of Alzheimer's disease, to certain signs *as* evidence; it focuses their attention toward the activities, routines, behaviors, and interactions that compose a patient's life beyond the clinic; it requires family members to evaluate, through a medicalized logic, whether those elements of daily life, as the patient goes about them, exhibit a marked departure from their knowledge of the person. Many of the actions and events that clinicians recognize as symptoms must be made visible outside a clinical or laboratory space. They are moments of routine disrupted, found in a person's home as unpaid bills or mismade recipes, in conversations with friends and family members as wrong names or tip-of-the-tongue words, in her car as forgotten directions or lapses in judgment of distances, and in her place of employment as lost computer literacy or long nights spent catching up. To mark these actions and events as symptoms of Alzheimer's disease, then, clinicians collect a medical history, a mechanism that relies on a diagnostic technology that the medical community finds most uncertain, even in ideal situations: the patient himself. In the context of Alzheimer's disease, though, the patient's ability to accurately narrate his own history is precisely one of the actions under question. So clinicians turn to, once again, an informant, "someone who knows them," in Dr. Edwards's language, well enough to be able to provide a narrative that clinicians can feel comfortable assuming is a more

accurate reflection of the patient's daily life. After its first use, Dr. Edwards' immediate switch to and continued use of "family" rather than "informant" makes clear who clinicians imagine the informant to be. Clinical understandings of "family" demonstrate underlying ideologies of family as a group of relations with intimate knowledge not only of each member's daily life but also an intersubjective understanding of their experience of that life.

Through these mechanisms, Alzheimer disease begins to appear in the patient's missed answers and in the caregiver's accounts. As diagnostic technology, families do critical work in the construction of the indexical chain, providing instances of the changes a person is noticing. Yet, ultimately, rather than finding something structural—some lesion—within a person's brain, the process of diagnosis comes to locate Alzheimer's disease in the temporalities, spaces, materialities, and relations of a person's everyday life.

For a person to be diagnosed with Alzheimer's disease, the symptoms she exhibits must interfere with her daily life. According to Memory Clinic criteria, "A dementia is defined as the loss of more than one area of intellectual functions, such as memory plus language or ability to perform tasks in order, **to the degree that it interferes with a person's daily functioning**" (emphasis in original).<sup>22</sup> It is distinguished from the memory loss and other cognitive development associated with normal aging, which the same document assures the reader present "nothing more than an inconvenience for most of us." The degree to which person's daily life is disrupted, however, is not something that can be made readily apparent in the

---

<sup>22</sup> This definition comes from a document written for a yearly training seminar, conducted by staff of the Memory Clinic and its associated Alzheimer's Disease Center, for directors of long-term care facilities. The criteria presented within the document closely mirror those of the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (2000), which is (along with ICD criteria) the standard diagnostic criteria used by clinicians.

neuropsychological testing or within any of the imaging scans or blood work that is typically done to rule out non-Alzheimer's forms of dementia. In order to ferret out the effects of a person's change in behaviors, clinicians turn to diagnostic means that elicit her medical history, seeking information that would indicate the extent of these effects beyond the clinic. While others have described this process of elicitation as the first in a series intended to abstract the patient and her symptoms from everyday life (Moriera 2010), here I argue that it actually is intended to do the exact opposite, that clinicians use the elicitation quite intentionally to make AD visible among the mundane concerns of the day-to-day.

The initial clinic history moves through several activities of self-care and social engagement that a person might be expected to do on a frequent basis. At what is considered the most basic level of self-care, clinicians ask about "activities of daily living" (ADLs), a series of activities such as bathing, dressing, eating, and toileting that have been marked and codified to measure a person's functionality and independence in self-care. In addition to these so-called "basic" ADLs, instrumental ADLs (e.g., money management, housework, taking medications) have also been articulated as activities necessary to remain independent within the community.

Within the Memory Clinic, the Review of Systems and Medical History form includes questions about the ADLs of bathing, grooming, eating, dressing, and toileting. On the form, the informant is to note how much assistance the person requires for each activity by checking a box—e.g., "Eats without assistance," "Eats with minor assistance," or "Requires extensive assistance for all meals"; within the interview, questions are more open-ended (e.g., "How does she do with eating?", "What do you do to help her?"), but similarly directed. Other activities about which clinicians inquire include cooking, driving, sleeping, and paying the bills and other

financial related matters. For younger people undergoing examination, as with Harold Lawton, often questions will center around employment and working routines: Is the person still working? Is she able to complete tasks she was able to do before? Does it take a lot longer? Can she use equipment that has been part of her job (e.g., computers)? Have co-workers noticed changes?<sup>23</sup>

Along with assessing whether or not a person's cognitive abilities interfere with daily activities to a significant enough extent, the use of ADLs within the medical history places Alzheimer disease amid the daily lives of persons and families in multiple ways. The dailiness of the activities denotes a routine temporality of domestic life: a person can be expected to engage in these activities every day, often multiple times a day. Alzheimer's disease is noted as a rupture to these routines; it breaks the rhythm of daily life. In addition, ADLs are used within the clinical interview to measure the "progress" of decline between medical visits. Decline, the overriding temporality of Alzheimer's disease, is marked in a person's changed ability to accomplish these domestic activities. A person's ability to make his own lunch the first year, but reliance upon his spouse to do so the following, becomes a measurement of decline, and that decreased ability becomes the evidence of the person's AD. The inclusion of these activities also evinces a sense of space; they place Alzheimer disease in bathrooms where accidents happen, around dinner tables where spoons are forgotten, and in closets where clothes cannot be found. Not only do

---

<sup>23</sup> Certainly younger persons are not the only ones for whom questions of employment are relevant. However, the majority of those I saw in the clinic who would be diagnosed with late-onset dementia were retired, while everyone who was dealing with young-onset dementia was still working at the time of diagnosis.

ADLs map onto place, but they make Alzheimer disease appear as an engagement with the materiality of daily, domestic ritual, that which shapes family and home.

Clinicians also interrogate the quality of patient's social lives, finding Alzheimer disease in the fabric of social relations. They will ask about whether the person has been more withdrawn in social situations, if she is quieter than normal or engaged in more solitary activities recently, if she has seemed depressed or has been overly angry or suspicious. Clinicians frequently talk about these shifts in terms of "changes in personality," but they become visible as disruptions between people, in the social rituals of daily life.

Through their clinical engagement, families are calibrated to see activities from ADLs to antisocial behaviors as evidence of Alzheimer disease. Such calibration occurs over time, and families learn to produce reports for clinicians that focus on changes in the kinds of activities that have been deemed important markers of the condition's progress from the beginning. Dr. Edwards, for example, often opens his conversation with family by asking, "What have you noticed?" Few families can provide a complete evidential profile of symptoms that he considers meaningful with only this broad prompt; frequently, families will have the moment where they "first noticed" something was amiss, others may have a few key examples of changes. Very quickly, though, Dr. Edwards will begin to narrow the discussion's focus, guiding family members to the moments of life in which he is most interested. Often families will talk about family or medical history, or bring up moments that they feel are examples of the presence of AD, that the clinician feels is irrelevant, and the clinician will try to pull the family member back to the series of topics above. Or, family members will skip over an area, talking a lot about, for example, changes in a person's mood and not mentioning that she is in a fair amount of credit

trouble after failing to pay her bills for several months. As the person is diagnosed and the family attends follow-up visits, most often once or twice a year, they begin to refine their ability to see AD in the same terms as their clinicians do. And, as they become attuned, clinicians begin to trust them more as well-calibrated diagnostic instruments.

Marty Evans, for example, had been coming to the Memory Clinic with his wife Vickie since he was diagnosed in 2009. He was a giant of a man, quick with a quip yet quietly serious about his diagnosis, while at first glance, she embodied the stereotype of a sharp-talking wife who would fit well in the cast of *The Sopranos*. In 2011, she started their annual visit to the clinic by requesting that she and the clinician speak alone first; she had a clear sense of the rhythm of a clinic visit and how to direct it. “The big thing,” she began, “is, um, two weeks ago he fell twice.” “Oh!” responded the clinician, as Vickie added, “In two days.” She went on to describe how each time Marty fell he was going down steps, once at their home and once while out running errands. These are accidents which, at first glance, might seem to have little to do with AD and much more to do with Marty’s weight. However, Vickie had become aware—through her time with Marty, at clinic visits, attending support groups, and doing research—that stairs often are difficult for people with Alzheimer’s disease as they begin to experience visuospatial changes; diminished depth perception can make the stairs effectively disappear. And the clinician clearly felt Vickie’s perceptions were properly calibrated, as they started talking about ways to address the falls as part of the changes associated with AD.

The linkages that become visible in the clinic are not between brain pathology and symptoms (or the more evidentially valued biomarkers and physical symptoms); it is the clinician, as non-fiction author, who narratively draws the links back to the brain. Rather, the

connections that emerge through the process of diagnosis are between symptoms and routines of daily life. These links strengthen the understanding of Alzheimer's disease as a family disease, placing the condition within the family's life and home in a way that allows clinicians who are discouraged by the lack of available treatment to turn to the family as a principle site of treatment and care intervention. Changes can be made to routines or houses. Communication strategies can be discussed to help disarm situations that have led to arguments. Caregivers can be trained in an attempt to reduce their stress from the "burden of care." Vickie's calibration that allowed her to properly notice and identify new evidence of Marty's Alzheimer disease was part of her process of realignment as a family caregiver. It also, however, was evidence that Alzheimer disease existed within their home and community—it was present in the relationship between Marty and the steps, his ability to move throughout the house and his yard. Once it was identified as that relation, the object of intervention expanded. No longer were Marty and his brain, an intervention target for which clinicians had few resources, being treated in the clinic. Instead, the stairs and daily activities involving them were the focus of treatment. After Vickie related what happened, she and the clinician brainstormed adaptations that could be made to the house stairs (e.g., painting the edges of each step a bright color to make it more noticeable, or using reflective tape).

## **Conclusion**

In order to be a disease—an entity that can be pointed to, marked through diagnosis, studied, and (ideally) treated—that entity must be located somewhere. Classically, in biomedicine, this is the individual human body. In this chapter, I have made the argument that,

while researchers and clinicians make continued attempts to find Alzheimer's disease in an individual's brain, clinicians in practice actually locate the condition in a person's everyday life. In order to do so, they appeal to that person's family for assistance: Family acts as the primary diagnostic technology that makes Alzheimer's disease visible in the materiality, routines, and relations of a person's daily life. Family members come to recognize certain signs (an ever-expanding range as time goes on) as indications of Alzheimer's disease.

Family members, whether the person themselves or another member, already have suspicions that something medical is occurring: It is that suspicion that initially draws them to the clinic. Sometimes the person and his family will be inclined to think that the difficulties are dementia related. With the families I worked with, in the context of young-onset Alzheimer's disease, this was particularly the case if the person had a dominantly inherited form of the condition or thought that they did because of a well-known family history. Alex Reynolds, who participated in the panel at the FADC conference along with Harold Lawton, has an extensive history of Alzheimer's disease on one side of his family. The day of the conference, when it was his turn to talk he told participants: "My father had it; his brother had it; his sister had it; the whole family on that side had it, and I knew that could happen to me." During my first interview with him and his wife Bridget, both confirmed that they "weren't surprised at all" when he received the diagnosis. Without a strong family history like Alex's, though, families still often find Alzheimer's disease a prime suspect. The Lawtons entertained the possibility of Alzheimer's disease enough to periodically evaluate Harold's actions in relation to the Alzheimer's Association's list of warning signs. Even when families did not initially suspect dementia, however—as those living with so-called sporadic cases of young-onset dementia did not because

of the age associations of the condition—they unfailingly preferred to interpret the cause of the changes they were noticing as somehow medical in nature. Often, for women, behavioral and personality changes that were eventually seen as evidence of dementia were understood through that diagnostic catch-all of female middle-age: menopause. In other instances, families thought that the person was depressed, and—especially with people who are eventually diagnosed with early-onset dementia—that is frequently a first diagnosis. In Kevin Smith’s case, he was doing almost constant travel for work as a technical manager for a major television network’s sports broadcasts; during certain sporting seasons, he would be traveling between cities every few days. As he was traveling, he and his wife Susan noticed that he was having more and more difficulties with remembering his current city. When he cut off a national, championship-level broadcast for several seconds in the midst of game play, they told me they knew something was wrong. “We didn’t know what it was, but we knew he had to go to the doctor,” Susan said. “I thought maybe he’d had a stroke. Maybe it was a brain tumor. But Alzheimer’s? Never!” Though, they both described their shock at the diagnosis while we talked, they knew something medical was amiss, even so far as to think it likely had something to do with the brain. Given the extent to which such things appear in the media as having severe medical consequences, even those who thought that it was stress or exhaustion did so within a medical framework.

The process of realignment, then, rather than one of medicalization, which presumes a prior non-medicalized family, might more accurately be conceptualized as one of medical specification, wherein conditions that are already suspected to be medical and relations which are already affected by those conditions both come to be further understood within specific expert biomedical frameworks. As families come to think of the changes the person is exhibiting as

“Alzheimer’s disease,” they come to understand their own lives in relation to it in its specific medical nature. The Reynolds placed Alex’s diagnosis without surprise within a longer family history of Alzheimer’s disease, while the Smiths found themselves and their expectations undercut not by the medical nature of Kevin’s condition, per se, but by the specific character of that medical condition.

In the following chapter, I turn to examine what exactly comes home with families once a diagnosis of Alzheimer disease has been conferred. What are the understandings of disease and caregiving that accompany the diagnosis? And how do these come to shape particular families as “caregiving” ones?

## **Chapter Two: Alzheimer's Live Here: The Ecological Niche of AD and Family Caregiving**

In August 2009, the Memory Clinic's support group held a book discussion. The group convened monthly in a small church, bringing people from as far away as Michigan, Indiana, and Wisconsin to a Chicago suburb, all living with early-onset Alzheimer's disease (AD). Over the course of two hours, members met, first, in an informal coffee hour with all participants and, second, in separate, smaller sections for family caregivers and those diagnosed. That day, rather than the more typical meeting format centered around member concerns and questions, the latter portion was what staff referred to "Support Group Book Club," focused on a recently published novel, *Still Alice*. The book's third-person limited perspective follows Alice Howland, renowned Harvard psychology professor who specializes in linguistics and language acquisition, detailing how she and her family live with early-onset Alzheimer's. It opens with Alice's increasing awareness that something is amiss as she forgets words during lectures or finds herself keeping ever-more detailed checklists, and soon she is diagnosed with early-onset AD. Told from her perspective, the story details both Alice's experience across two years while also turning a lens onto the family's challenges to come to terms with the diagnosis. As people's comments swirled around the ways both Alice and family members dealt with her condition, I noted the ways the conversation in the breakout session of family caregivers highlighted the moral and relational complexity of AD and family caregiving. Later, as I talked with Janis about the discussion among the group of those diagnosed, the emergence of Alzheimer's disease in people's daily lives was evident. As always, when amongst the support group, I was struck by the inextricability of Alzheimer's disease and family caregiving.

In the section for diagnosed people, the conversation that morning focused on how the author Lisa Genova portrayed Alzheimer's disease through Alice's experience. Assuming that not everyone had read the novel, Janis O'Connor, the social worker who moderated the section, had chosen a few key events to discuss. Later, she talked about how the group was particularly interested in a moment early on when Alice is running a jogging route she knows well through a part of Cambridge that "had been her stomping ground for over twenty-five years" (2007: 25). Suddenly she doesn't know where she is; passing familiar landmarks, stores, and signs, she "told herself she could still read and recognize. None of this helped. It all lacked a context" (26). Group members discussed knowing that feeling. Harold Lawton described it as walking on Swiss cheese and unexpectedly falling through a hole, dropping out of life for a period of time. These moments when Alzheimer's became noticeable and how Genova's description compared to members' lives provided the bulk of the conversation.

Down the hall, where these people's family members were also discussing the novel, conversation focused not on the interpretation of Alice's experience but rather on the family's reactions, experiences, and decisions around caregiving. Genova uses the family to present a variety of caregiving archetypes. While I could imagine other support groups, filled largely with children caring for their parents who had been diagnosed later in life, focusing discussion on Alice's three children, the group of family members assembled—spouses, all—were most concerned with Alice's husband John, a successful biologist who decides in the latter half of the novel to pursue a career opportunity in another city rather than stay and act as his wife's caregiver. "He was being a shit!" one woman exclaimed, and while everyone laughed, the evaluation of John's decision struck a nerve. Another group member, Shawna Johnson talked

about the possibility of a sabbatical that Alice raises, “I thought, ‘Okay, I have a career, too.’ But if my job let me have a sabbatical? ...I would take it!” Miriam, whose husband Jacob was upstairs in a music-focused group for diagnosed persons, said her first thought was, “Well, that’s a typical man.” But Heidi, Harold’s wife, was quick to bring up “the men here, and all they’ve done,” referring to the number of men who attended the group as spousal caregivers. Miriam conceded and brought up the point that John was young, far from any benefits of retirement, so for him to stop working at that point would have been foolish, as he was going to have to continue with his life after Alice died. Shawna, in a recuperative moment, reminded everyone that the book was written from Alice’s perspective so there was probably a lot about John that they couldn’t know. Charlotte, the advanced practice nurse who was moderating the group, spoke up, at that point, “When I was reading that section, I was wondering why the author was doing that. And I was thinking it was probably to display just the idea that, you know, here’s a husband..., John [who] thinks of Alice as Alice. Who he married. And John never transitions to Alice (0.2) now.” During the brief pause, Shawna jumped in, such that Charlotte’s “now” was overlaid with Shawna words: “with Alzheimer’s.” Charlotte continued, “So it almost seemed like every action he took in this story was based on who Alice was to him when they got married. And Alice never would have told him not to take that job. ...And it just shows his lack of ability to kind of go with her on the journey. And he never really went with her, you know?”

At one point late in the family caregiver’s session that morning, Heidi said: “This makes it very clear to me that this group has to be separate from the [diagnosed people’s] group that Harold’s in because we’re not focused on the book. We’re focused on ourselves in relationship to the book. It’s a different conversation than the one I would’ve thought we were gonna have,

but—which is, that this is right.” While staff called these meetings “Book Club,” the conventions were different; Heidi gave voice to the fact that, rather than evaluating the book as a piece of writing, the book became a lens, through which the group members refracted their own experience through that of the characters. Alice losing her way while running became a touchstone for talking about the experience in the lives of those diagnosed—AD as a moment of “dropping out” could be identified, described, discussed, and compared; it gained the edges of definition. In the course of their conversation about John, family caregivers grappled with their own positioning as caregivers, what that meant for themselves, those for whom they cared, and their day-to-day lives. As they evaluated John and his decisions, drawing on personal experience and popular discourses, they placed themselves in the moral landscape of AD and family caregiving. To Heidi, it was clear that the moral grapplings of caregiving—involving evaluations of personhood and the strength of relational bonds—were not to be shared with their spouses, especially as discussion moved so quickly from the fictional world of Alice and John to group members’ own lives. Both groups discussed and enacted entangled versions of Alzheimer’s disease and family caregiving—in the content and shape of their conversations, the ways they interacted, how they found and entered the room and how they left at the end, the ways they referred to each other, the guidance of moderators.

This chapter examines those entanglements of Alzheimer’s and family caregiving, specifically tracing how both are articulated across the dominant narrative of Alzheimer’s disease, the primary symptom of memory loss, the clinical focus on activities, and the temporalities of decline and the coming cure. I argue that both are the product of an ecological niche, a particular historical space in which their emergence becomes uniquely possible. Through

this, I demonstrate that, rather than ahistorical brain pathology and natural obligation of family, they are inextricably bound social formations rooted in a historical moment in the early twenty-first century United States. In the previous chapter, I argued that diagnosis is the beginning of a process that locates Alzheimer's disease within a family's daily life, a process which interpellates both a diagnosed person and a family caregiver. Following that, this chapter asks: After a family leaves the clinic with a diagnosis of AD, what comes home with them? What ideas and expectations of Alzheimer's and of family caregiving become part of their daily lives? How do these understandings provide the foundation for how families come to understand their lives, their projects of family-making, and their relationship?

### **The Ecological Niche of AD and Family Caregiving**

The nature of Alzheimer's disease and family caregiving in the US public imagination is the product of a cultural and historical moment that has opened across the latter half of the twentieth century. Together, I argue, entangled condition and intervention exist within what Ian Hacking (2002) has called an ecological niche, a historically contingent space that has made both AD and family caregiving, as they were understood by the people with whom I worked, possible.<sup>1</sup> As it articulates a historical moment, an ecological niche also is a metaphor for thinking about the way that a number of "vectors," or social forces, must come into proper alignment, creating the space for an instantiation of a phenomenon: The phenomenon must fit

---

<sup>1</sup> In his work on fugue, a transient mental illness, Hacking uses the concept of an ecological niche to describe the sudden ascendance and equally rapid disappearance of fugue as a recognized mental illness in certain parts of the world around the turn of the twentieth century. He also has discussed multiple personality disorder (or dissociative identity disorder) as emergent through the alignment of a similar niche.

within a framework of medical classification; it must be observable; it must highlight a culturally salient, moralized polarity; and it must offer the possibility of a solution to a social problem not otherwise available.<sup>2</sup> As Hacking writes, “In the presence of relevant vectors, the illness flourishes; in their absence, it does not” (2002: 82). The intertwined phenomenon of Alzheimer’s disease and family caregiving is an exemplar of just such an ecological niche. AD and family caregiving have been medicalized and through the process, have become visible as national discourse, public health concern, and moments of everyday life. And together, they highlight a polarity of dependency, along a moralized continuum of intervention from elimination of the medicalized condition to abandonment. Family caregiving is acceptable because its intentionality is morally valued, even while it is seen as unable to act upon that virtue. Thus, it’s not that family caregivers don’t want to do any good, it’s just that they can’t. They are unable to effect a change, or at least one that matters, despite their moral calling and near constant action—a paradox examined further in the following chapter. Family caregiving also provides some version of a solution to the problem of dependency, articulated as a “crisis” of care or aging. Family caregiving is, while far from independence, an acceptable alternative to dependency upon social welfare, ideally invisible outside the home. In this way, family caregiving in the context of Alzheimer’s disease is a solution on par with quarantine, more closely resembling public health projects designed to contain contagion (e.g., Shah 2001). Family caregiving, as seen by the state, protects against the spread of dependency engendered by Alzheimer’s.

---

<sup>2</sup> While Hacking’s framework comprised four vectors, he was careful to insist that they were four among many: “One point of the metaphor of an ecological niche is the complexity—and sheer size—of the manifold of elements that makes a new type of diagnosis possible” (86).

Understood within an ecological niche, the co-constitutive and interdependent nature of AD and family caregiving becomes clear. To have Alzheimer's is, in many ways, to have a caregiver. Likewise, to be a family member of someone with AD often is to be their caregiver. According to the Alzheimer's Association's "2016 Alzheimer's Disease Facts and Figures," "Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. ...In 2015, the 15.9 million family and other paid caregivers of people with Alzheimer's disease and other dementias provided an estimated 18.1 billion hours of unpaid care" (Alzheimer's Association 2015: 32, 35).<sup>3</sup> The majority of people with AD will have care provided by a family member or other informal caregiver at some point during the course of their illness.

Depictions of Alzheimer's have long illustrated the conceptions of the illness and family caregiving as strongly intertwined. As sociologist Jaber Gubrium has characterized the relationship between the condition, person diagnosed, and caregiver: "Caregivers are commonly referred to as the disease's 'second victims,' affirming that, in relation to the everyday subjectivities of the caregiving experience, there are always two inner worlds in question. Both the sufferer and the caregiver are disease victims" (Gubrium 2000: 194). The breadth of the scholarly and biomedical work (e.g., Kleinman 2007, 2009; Mitnick, Leffler, and Hood 2010; Taylor 2008), policy literature (e.g., Binstock, Post, and Whitehouse, 1992; US Congress 1990), memoirs and self-help guides directed toward caregivers themselves (e.g., Bayley 1999; Mace

---

<sup>3</sup> As they also estimate, "Only a small percentage of older adults with dementia do not receive help from family members or other informal care providers (8 percent). Of these individuals, more than 40 percent live alone, perhaps making it more difficult to ask for and receive informal care" (2016: 32). This is a critical population to engage with, as researchers. Yet, it is important to note that, even in family's absence, care and its parameters are structured around family.

and Rabins 2006; Markut and Crane; Witchel 2012), and accounts in the popular media (e.g., Genova 2007; Jenkins 2007; Polley 2006) points to the strength and ubiquity of this tie in the U.S. imaginary.

Family caregiving—as a health intervention thought possible in the US public imaginary and political landscape—came to the fore alongside what has been called the “rediscovery” of Alzheimer’s disease in the 1970s (Katzman and Bick 2000). The history of Alzheimer’s disease is commonly understood as having three periods (Ballenger 2006, Leibling 2008, Lock 2013). The initial period, at the beginning of the twentieth century, was one of discovery, classification, and early medical research. In the US, this initial burst of interest was followed by a period, extending from the 1920s to the 70s, when Alzheimer’s disease became the object of interest for psychiatrists and psychodynamic therapists, focusing on the social roots of senility. In the current period, Alzheimer’s emerged as a national, public health concern, firmly embraced by biomedicine as the hallmark of an impending aging and care crisis. Family caregivers were critical to this rise. Patrick Fox (1989, see also Chaufen et al 2012) has convincingly argued that Alzheimer disease rose to public consciousness through the development of a social movement coordinated by family caregivers and advocates, researchers, and policy makers. Alzheimer’s was reconceptualized during this period, shifting it from a relatively rare condition among younger persons to a growing epidemic of cognitive decline among the elderly, worthy of political, social, and importantly financial attention.

Family caregiving appeared as a politicized, medicalized intervention in the latter half of the twentieth century, also largely in response to what often is perceived as an aging or care

crisis.<sup>4</sup> Demographic shifts in the United States have increasingly been noted, often with trepidation as the age structure has shifted from a pyramidal shape, with a greater number of young people, to more of a square shape that reflects more equitable numbers of young and old people. In addition, much of this growth at the top of the age structure is among the oldest-old (those over 85), who often require the most (and most costly) interventions. The fear that drives this crisis discourse is two-pronged: one, as there are fewer workers paying into government welfare programs for the elderly (most prominently Social Security) and more older people drawing upon those resources, the funds will quickly be drained; and two, there will be fewer young people to care for the growing number of elderly, who are expected to be increasingly dependent as they age. Through this link between aging and dependency, between bodies that are undergoing the physiological processes of aging and persons who are seen no longer as productive but instead as a burden, is made as aging becomes a crisis, one which is synonymous with a care crisis.

Family caregiving becomes the naturalized, deeply gendered intervention for certain kinds of health care needs, notably long-term care for people rendered undeniably dependent,

---

<sup>4</sup> In its most hyperbolic expression, conservative Peter G. Peterson has likened aging as one of the potential four horsemen, placing “the graying of the developed world’s population” alongside other “major global hazards”: “the proliferation of nuclear, biological, and chemical weapons, other types of high-tech terrorism, deadly super viruses, extreme climate change, the financial, economic, and political aftershocks of globalization, and the violent ethnic explosions waiting to be detonated in today’s unsteady new democracies” (Peterson 1999: 42). Taking a more measured tone, the Rosalynn Carter Institute for Caregiving, in a 2010 publication entitled, “Averting the Care Crisis: Why We Must Act Now,” wrote: “Estimates have consistently projected that the need for family caregiving in the United States (U.S.) will escalate significantly in the coming decades. This increase in demand can be attributed to several key trends, including an aging demographic, increased longevity, the growing burden of chronic illnesses, and an overburdened formal healthcare system” (5).

through what sociologist Sandra Levitsky (2014) has termed “the ideology of family responsibility.” In her recent work, Levitsky describes family caregiving understood within the this ideology as “a natural or inherent moral obligation, superior to any other form of care, such as paid home health care or institutional care” (2014: 5). As she writes, this ideology rests on an unchanging notion of what caregiving, coupled with an intense moral framework of obligation.

Considered as inextricably emergent with Alzheimer’s over the last five decades, the sociohistorically specific nature of family caregiving as a formation of practices, knowledges, relations, and morality is evident, refuting the notion that family caregiving is a naturalized relationship of family in the home that can be read back in history. While scholars have been careful to mark the periodization of Alzheimer’s disease, they have regarded family caregiving as a narrative of continuity that implicitly elides the specificity of family caregiving in the current historical moment. The standard narrative is one that traces the professionalization, across the late nineteenth and early twentieth centuries, of the labor of women in the home to help people through life course transitions of birth and death, provide treatment or palliative care when people were ill, and offer assistance to those experiencing disability (Abel 2000, Benjamin 2003, Buhler-Wilkerson 2001, Glenn 2010, Reverby 1987). This work became consolidated as the expertise of physicians, and as part of this process, it became separated from women’s domestic duties and moved out of the home to a hospital or physician’s office. As chronic illness has come to fore of the public health agenda, however, the possibility of providing these services at home has once again become attractive, particularly for those who are not in the grip of the acute health incidents around which the US health care system had been structured. The corporatization of hospitals, development of Medicare and Medicaid, rise of managed care and a

prospective payment system for hospital related costs, and retrenchment of an already anemic state welfare system all furthers this interest in the home as an extension of the health care system. With this, health care returns to the home, once again to be attended to by families' female members. In the US public imagination of caregiving, its underlying structure has not changed: Families have always cared for their dependent members; changing demographics, health care supports, care recipient needs, and care technologies, however, have changed the frequency of that caregiving on a national scale and the kinds of tasks caregivers undertake (Schulz and Martire 2004).

The stakes of this narrative of continuity are paramount. The domestic labor of women tending to people's health has gained critically necessary visibility through the efforts of feminist scholars who peeked behind the front door of the domestic, shining a light on the extraordinary amount of labor that goes unacknowledged in a political economic system that only values labor in the public sphere (e.g., Abel 2001; Hochschild 1983, 2012; Kittay 1999; Noddings 1984, Reverby 1987, Tronto 1993). The imposed invisibility of this work devalued not only the labor but those engaged in it. As Hooeyman and Gonyea write in their introduction to the volume *Feminist Perspectives on Family Care*:

We define long-term care of relatives with a disability as a central feminist issue, because such care depends on women's unpaid and often invisible labor. An underlying assumption of feminism is that women as caregivers have historically been oppressed within both the home and the labor market. Not only have women been relegated to the private sphere, but their lives within that sphere have been made invisible and their voices have been silenced. (1995: 6<sup>5</sup>)

---

<sup>5</sup> Emily Abel provides an interesting complication to this in her book on women caring for kin from the mid-19th to mid-20th centuries (2000). As she writes, "A principal theme in much feminist writing today is that women are compelled to provide care by oppressive ideological and

Not only did scholars detail the ways that women and their labor had been made invisible, but they asserted that women have “internalized the altruistic ideal; society has capitalized on it. With women prepared to remain or return to the home to care, society is provided a ready-made ‘reserve army’ of nurses, an army that does not need hospitals to be built for it to work in and does not need wages to be paid to it, because, *it is assumed*, its members are already provided for by being dependent on, and thus supported by, wage-earning men” (Dalley 1988: 24, emphasis in original). This scholarship has been critical to revising the historical record on women’s involvement in the evolving US health care system, and has helped to shape a moment in which caregiving can be conceptualized and measured as work. An understanding of caregiving as labor has come to structure political and public understandings of it.

Yet, in advancing a narrative of continuity, this scholarship implicitly reinscribes the naturalization of this labor as domestic and female, underwriting the ideology of family responsibility. Caregiving comes to be understood as the ahistorical purview of an idealized family, wherein family members (read: women) have always cared for their own, out of a sense of reciprocal obligation or some other notion of kin responsibility. This understanding shapes policy, as Levitsky writes, restricting both the provision of public services to those instances “where there is no family or after family resources have been exhausted” and the support to families to only that which is absolutely necessary “to reinforce—and avoid weakening—family-based care” (2014: 5). It also shapes the moral imagination of family caregiving within the US:

---

material forces. Have women caregivers simply been responding to external pressures? Did care giving obligations conflict with women's own self-determination? Or, in fact, did caregiving contribute to women's autonomy and maturity? How have poor women, especially women of color, struggled to be able to care for intimates?” (4)

Not only is caregiving what families have always done, it also is what they should do. This is the position from which the support group members levy a critique against John from the novel *Still Alice* (even Charlotte, who attempts to complicate by offering an alternative reading of John's actions, ends up positing that he just is not able to truly be a caregiver).

### **The Narrative of Alzheimer's: A Structuring Story of Loss**

Alzheimer disease is mythical in its power. The words "Alzheimer's disease" evoke a range of emotions—fear, anger, hatred, sadness, pity—because they are saturated in a well-articulated narrative that circulates throughout the US imaginary. Developed and refined by the protagonists of Alzheimer's activism, the narrative has changed little over the past forty years. Rather, the elemental structure has only grown more stable even as the narrative waters have risen, seeping into not only popular understandings of the condition but also families' daily lives. However it is elaborated, the narrative has standard elements, illustrated below, that structure its story of loss.

Alzheimer's disease is a horrific way to die:

First, Alzheimer's disease strips away memories. Next, its victims lose their independence, and then their very personalities. Finally, people with Alzheimer's cannot even control their most basic bodily functions, such as speaking, walking, and eating. Many victims succumb to complications of the disease, including deadly infections. For those who avoid these complications, life ends with a final act of forgetting: the brain simply forgets how to breathe. (Alzheimer's Study Group 2009, 8)<sup>6</sup>

---

<sup>6</sup> As the Alzheimer's Study Group writes in their final report: "The Alzheimer's Study Group was established on July 11, 2007 under the auspices of the Congressional Task Force on Alzheimer's Disease with the charge of creating a National Alzheimer's Strategic Plan to overcome America's mounting Alzheimer's crisis. With the delivery of this plan on March 25,

Not only is the person with Alzheimer's disease devastated, so is their family, who must sit by and watch it happen:

The toll Alzheimer's takes on caregivers is a burden financially, physically and emotionally. Just imagine the tragedy of watching your loved one, the light of your life, slowly disappearing day by day. (Alzheimer's Association 2011: 8)<sup>7</sup>

The tragedy of Alzheimer's disease, though, is not just personal. It is national, even global, in scale; it has enormous financial implications, and it will only get worse:

Not only is it a crisis for individuals—Alzheimer's is a devastating condition for those with the disease and their families—but, because it is extremely costly, Alzheimer's is becoming a national economic crisis as well. Alzheimer's disease clouds our Nation's future. (ASG 2009, 7)

This epidemic of Alzheimer's disease will affect us all, if we do nothing:

We are going to pay for Alzheimer's one way or the other. The consequences of doing nothing will be continuing to pay for caring — and we should ensure more effective care for those with this devastating disease. But if we commit now to **curing** — to fund research that leads to a breakthrough — we can save billions of dollars. A commitment today to innovation, to finding a cure, will yield the savings of tomorrow. (AA 2011: 10)

But the world without Alzheimer's exists in a tantalizingly close future:

With the cooperation of the medical and research communities, we are at a tipping point. We have the ideas, the technology and the will...[a]nd we have reason for genuine and tangible hope that will fundamentally change the nature of the disease. Every day brings us closer to a cure.... For the first time in history, there is real hope in emerging science that we can overcome Alzheimer's disease and

---

2009, the members of Alzheimer's Study Group ended their service together" (2007: 45). The plan was used as the foundation for the development of the National Alzheimer's Project Act, signed into law by President Obama in 2011. The Act mandates the creation of a national plan to address Alzheimer's as an impending crisis.

<sup>7</sup> The Alzheimer's Association report, "generation alzheimer's: the defining disease of the baby boomers," was a call-to-arms for a generation who started turning 65 in 2011, the year the report was published. I use it here as a particularly explicit exemplar of the Association's rhetoric.

that the day is near when Alzheimer's does **not** need to be a death sentence<sup>8</sup> (AA 2011: 14).

As a person is diagnosed with Alzheimer's disease and she and her family learn more about it, they come to understand themselves largely in terms of this narrative and the roadmap it provides for the rest of their lives. The families with whom I worked frequently talked about, both explicitly and less so, the elements contained within the narrative—memory loss, decline that is tracked through a person's inability to complete activities, a corresponding increased burden felt across the family, a chronically terminal condition, a swelling epidemic. As the remainder of the chapter demonstrates, these elements come to shape the contours of both AD and family caregiving in this ecological niche.

### **Memory: Alzheimer's Disease's Most Famous Symptom**

*"First, Alzheimer's disease strips away memories." (ASG 2009: 8)*

When a person talks about Alzheimer disease, inevitably memory is one of the first, if not the first, topics mentioned. Memory overrides all else. In the opening of chapter one, the Lawtons began to wonder if Harold had the early signs of Alzheimer's because of his occasional lapses of memory. Heidi talked about them going through the Alzheimer's Association's "10 warning signs of Alzheimer's", and the first one is "Memory loss that disrupts daily life" (Alzheimer's Association, accessed March 26, 2015). The Association writes: "One of the most common signs of Alzheimer's is memory loss, especially forgetting recently learned information.

---

<sup>8</sup> As the reader's eyes reach the end of that line, almost invited to fill in the ghosted "as it is now," the distinction of futures within the logic of the coming cure, discussed further in chapter four, becomes clear.

Others include forgetting important dates or events; asking for the same information over and over; increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.<sup>9</sup> Several of the other signs could be (and most often *are*) glossed as memory troubles: misplacing items, problems with familiar tasks such as driving, difficulty balancing a checkbook, losing track of time, trouble finding words. Memory bleeds out into daily thought and conversation. Most months at Memory Clinic support group meetings, one of the church's maintenance personnel, an older gentleman would stop by the sign-in table and chat with Janis. Without fail, at some point during their brief interactions, he would joke about remembering that the meeting was that morning, "Guess that means I'm not ready to start coming yet, eh?" They would both laugh, and Janis would reply, "No, not yet." Janis most frequently referred to the members of the group she led, for people diagnosed with early-onset dementia who wanted to talk about it, as "people experiencing some memory issues". The privileging of memory as the dominant symptom of narrativized Alzheimer's has profound effects on families, rippling through both how families' understandings of AD as a disease located within the body of the person diagnosed and their conceptualization of the diagnosed person's self, the loss of which is threatened as memory fades.

---

<sup>9</sup> Notice the pronominal use. Even in a checklist of "early signs and symptoms", a person's capacity is already in question and a caregiver assumed.

### *Memory Locates Alzheimer's Disease*

The focus on memory and its loss as central to understanding the condition of Alzheimer's disease helps families and clinicians locate the condition in the fleshy matter of the brain. As discussed in the previous chapter, families become a kind of diagnostic technology that makes Alzheimer's disease visible in their daily lives and linking those moments of visibility to an individual's brain pathology, the practice Moreira refers to as individualizing. In this practice, memory is a primary binding agent between the visible symptoms—activities or behaviors—to changes in brain pathology: as people invoke it, the two are pulled into the same frame.

Joanne Moore, for example, whose husband Alan was diagnosed with early-onset Alzheimer's disease when he was fifty-one, talked about the changes Alan exhibited in terms of memory loss, specifically his short term memory. Once she told me, in response to a question about how they were doing, that Alan was having trouble filling the bird feeders in their backyard. They have several scattered throughout the separate beds of their sprawling garden, and as she told me, "He filled two, but then not the rest. I asked him to finish, and he got more food, but then went on to something else." Although there are a number of ways his cognitive changes could have affected Alan in those moments, including shifting attention, a difficulty following the steps of directions, or perceptual changes that make finding the feeders challenging, when I asked her if she understood this as a result of memory, she responded without a pause, "Absolutely. He forgets them." She located the memory loss she saw evidenced in these moments in Alan's brain: "For example, I just fixed all his coats in his closet. He tries, but he fixes them all wrong," she told me, "It's stuff I wish people could see. The towel is this way. T-shirts." As she talked, she embodied the askew clothing and towels, arms dangling

akimbo, shoulders at an angle, neck crooked. Then she said, frowning, as though to Alan, “Your poor brain.” A “poor” brain, increasingly altered by Alzheimer’s, became visible in off-kilter clothing in the closets of their home.

In *Still Alice*, the first pages also narratively link memory and brain pathology. In the opening scene, Alice remembers a “crazed morning” she spent “looking all over the house and then in her office for her Blackberry charger, ...only to discover [it] later that night plugged in the socket next to her side of the bed, where she should have known to look” (2007: 4-5). In the following scene, she is unable to call up the word “lexicon” during an invited talk at Stanford:

She simply couldn’t find the word. She had a loose sense of what she wanted to say, but the word itself eluded her. Gone. She didn’t know the first letter or what the word sounded like or how many syllables it had. It wasn’t on the tip of her tongue. (2007: 11).<sup>10</sup>

These two scenes follow the very opening of the book, a short, 75-word description of deviant brain function:

*Even then, more than a year earlier, there were neurons in her head, not far from her ears, that were being strangled to death, too quietly for her to hear them. Some would argue that things were going so insidiously wrong that the neurons themselves initiated events that would lead to their own destruction. Whether it was molecular murder or cellular suicide, they were unable to warn her of what was happening before they died* (2007: 1, italics in original).

The links between brain pathology and symptoms were unsurprising to the group that morning; neither the family caregiver group or the group of those diagnosed mentioned them during the discussion.

---

<sup>10</sup> The Memory Clinic support group staff would note to diagnosed people and family members the difference between a memory being “gone” and just harder to find. More than once, Janis would explain it as being unable to come up with a word in the moment, but waking up in the middle of the night, remembering it. That’s normal, she would say, That’s not Alzheimer’s.

## *Memory and the Loss of Self*

As memory binds moments of daily life to the tangles and plaques of AD, memory loss also casts Alzheimer disease as the “most feared disease in America” (Marist Poll 2012).<sup>11</sup> While memory loss—specifically, a diminished capacity in short-term memory—is one of the first noticeable signs that come to mark a person as having AD, that alone does not explain the strength of the metonymic association between symptom and condition. Rather, as others have discussed (e.g., Ballenger 2006, Basting 2009, Cohen 1998, McLean 2007, Pohlman 2010), the power of memory is an affective one, and the emotion engendered is fear. Fear is what prompts the anxious question when a person misplaces her keys or cannot think of a word or a friend’s name, “Is it Alzheimer’s?”

The intensity of the fear arises from the relationship between a person’s self and her memory as it is understood within a “hypercognitive” US society (Post 2000).<sup>12</sup> As ethicist Stephen G. Post posits, the American ethos of selfhood is one of hypercognitivity that privileges rationality as the seat of the self. In the discourse of Alzheimer’s, rationality comes to be synonymous with memory, which in turn comes to be seen as both the archive and enactment of a person’s self. In his book on Alzheimer disease (aptly titled, *The Forgetting*), journalist David Shenk encapsulates the power of the memory discourse: “We are the sum of our memories.

---

<sup>11</sup> As Lawrence Cohen has written, “The centrality of Alzheimer’s in America...is marked by its key symptom, forgetfulness” (1998: 126). Also, Pohlman’s description of memory as stand-in for the soul

<sup>12</sup> As Post writes (2000: 249): “Were ours *not* a hypercognitive society, would we fear dementia enough to label it AD at a certain threshold? If we in the West did not place so much value on autonomy, the Enlightenment ideal of independent rational choice, would we be worried enough about the interdependence of dementia to label it AD? ...If we were not a culture that imposes the image of a youthful and fully intact mind on the old-old, would we so stigmatize dementia as to label AD as, in the words of Lewis Thomas, ‘the disease of the century?’”

Everything we know, everything we perceive, every movement we make is shaped by them” (2003: 16). As archive, memory is the place where a person collects her past and knowledge of the world—it is that which allows Shenk’s summation. More than collection, it must also be ordered properly, the archive’s files indexed and accessible.<sup>13</sup>

Within the ideology of American selfhood, memory is understood as a critical tool for producing coherence of a person’s essential self—who that person really is—from moment to moment, day to day, context to context.<sup>14</sup> Coherence, a kind of internal connectivity between the points of one’s life, is highly valued in this hypercognitive logic as evidence of one’s rationality and, thus, intact selfhood. And, importantly, coherence must be performable and verifiable—it must be accessible not only to one’s self, but also to others.<sup>15</sup> As in Shenk’s articulation of a

---

<sup>13</sup> Basting critiques this mechanized, computerized concept of memory: “Thanks to the computer, the camera, and the museum, we have a tendency to think of a memory as a bit of information that is stored away and can be retrieved on demand, as a photograph or video that objectively captures all details of a moment, or as an artifact that, with the right care, will remain intact for centuries. But in reality, a memory is none of these things. When information is encoded, it does create a physical change in the brain. But we filter retrieved memories through who we have become and all the subsequent experiences we’ve had since the moment that piece of information entered our minds. A memory is not an object preserved in the museum of our minds. It is a living, changeable thing that is shaped by who we are when we encode it and by who we are when we retrieve it” (2009: 18).

<sup>14</sup> Ballenger writes: “In the antebellum period, hierarchical social relations eroded with the market revolution and the triumph of a liberal social order. Since then, the notion of selfhood has grown increasingly problematic for all Americans. Selfhood was no longer an ascribed status but had to be carefully and willfully constructed by every individual. Constructing a self was further complicated in the late nineteenth century by the increasing complexity and power that external social forces exerted on the individual-industrial production, bureaucratic governance, and mass consumption. In light of these changes, the loss of the ability to independently sustain a coherent self-narrative—a loss that dementia entails—has come to be considered the most dreadful of all losses” (2006: 9).

<sup>15</sup> This is the critique that Athena McLean is making when she talks about the distinction between coherence and facticity. As she writes, drawing on the work of James Fernandez and Catherine Ewing, “Coherence is a symbolic process that depends more on that unity of feeling—an affective state—than on logical rules of text or even on actual past experience” (2006: 171).

commonly-held understanding of memory's centrality, memory, along with an ability to communicate, is seen as the evidence that a person connects with the external world.<sup>16</sup> As enactment, memory is a shorthand for the process of recall and communication it allows a person; memory is the work a person does to draw upon her past and narrate that past coherently to another. Memory is a personal archive of that which a person has encountered, and drawing upon it is proof that a person has lived in the world—and continues to do so. As memory falters, the assumption that a person continues to live in and connect with the world is shaken. A persistent need to verify and validate this connection is at the foundation of questions about recognition: “Does she still recognize you?” “Do you know who I am?”<sup>17</sup> As both archive and enactment, the ideology of selfhood casts memory as critical for a person's personal and social continuity. When this continuity increasingly appears disrupted, fragmented as a person's memory fades, her “self”—the core of who she is—comes to be seen as lost.<sup>18</sup>

---

<sup>16</sup> As historian Jesse Ballenger writes, “The anguish of Alzheimer's disease was not simply caused by the pain and humiliation it added to a life. All chronic diseases did as much. Alzheimer's disease was the worst of all diseases for what it took away—memory and language, the skills necessary for the maintenance of selfhood” (2006: 155). Of course, within the logic of memory, the loss of language and the ability to verbally communicate (by far, the most privileged form of communication in the United States) is predicated upon a prior loss of memory. That is, a person no longer has the ability to verbally communicate because they have forgotten how to do so.

<sup>17</sup> For a critique of these questions of recognition, see Taylor 2008.

<sup>18</sup> To better index the interiority represented through the “self” discourse, Annette Leibing turns to the use of “soul.” As she writes: “The notion of the soul is a good example of how an attribution of interiority is a moral positioning. The soul has various meanings, even among people who share similar cultural values (Leibing 2006b). However, what all these meanings have in common is that the soul is something essential to a human (sometimes also to animals, plants, or objects); it is “the immaterial aspect or essence of a human being, that which confers individuality and humanity...” (2008: 181)

“Loss of self” is an entrenched narrative trope of Alzheimer’s discourse, as diagnosed people have been described as “empty shells” or “the living dead” (Gubrium 1986, Herskovits 1995).<sup>19</sup> At the heart of this understanding of how Alzheimer’s affects a person is the fear that “AD represents the loss of all those qualities by which we have come to define our humanness” (Robertson 1990: 436). This understanding of lost self wound through the lives of my informants. While *Still Alice* worked hard to avoid the trope of loss—the final scene in the novel is Alice connecting with her daughter, an actress, over a monologue—other literature we read was more insistent about some element of lost “humanness,” despite the support group staff’s commitment to fighting the discourse. One book, for example, references a common metaphor in its title: *Jan’s Story: Love Lost to the Long Goodbye of Alzheimer’s* (Petersen 2010).<sup>20</sup> Another, entitled *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief* (2011), is by Pauline Boss, a family studies scholar who posited a theory of ambiguous loss—loss felt when a person is not wholly gone, but rather either physically absent but psychologically present or psychologically absent but physically present. While a more complex

---

<sup>19</sup> Janelle Taylor describes these “gothic” or “zombie” variants of a horror genre (2008). She writes: “Both the gothic and the zombie variants of the Alzheimer’s narrative depart from the same basic premise: the body may continue to live, but the person with Alzheimer’s is dead, gone, no longer there, no longer a person. He or she does not know your name, does not “recognize” you, therefore cannot “care” about you, but you must “care” for him or her—and such “care” is conceived as an unending toil of unrelieved grimness” (322).

<sup>20</sup> In the penultimate chapter of the memoir, the author describes a conversation with a nurse practitioner and pastoral counselor. She shared a story of helping a woman to recognize the “hard and sad but final” truth of “Alzheimer’s acceptance.” To do so, she showed the woman images of her mother’s MRI scans, saying “She doesn’t have any brain left.” “It was shocking,” she tells the author, “but the woman finally realized that *her mother was gone* and would exist only in her memory.” She then goes on to ask: “*How much of her, the Jan that you married, is still there?* . . . There is a time when families have to recognize that the physical body is *no longer the person they knew* and loved and move on. You don’t stop loving, you just do it in a way so as not to hurt or scare *this stranger*” (187, emphasis added).

version of lost selves, the theory of ambiguous loss still rests on the notion that a diagnosed person is “gone—but still there” (3). As many scholars have critiqued the loss of self discourse, the danger of it is that, once a person understands another as lost, as essentially no longer a person, the potential that he will treat the other as less than human is high. The threat of social death is real. Despite this criticism, discussed below, the discourse of lost selves remains pervasive.

The families with whom I worked, notably, articulated a more complicated narratives of loss: a loss of relations or a recognition of the self not as lost, but rather hidden behind Alzheimer’s.<sup>21</sup> Only one person, when speaking of his diagnosed wife, would sometimes refer to her as “gone.” More frequently, family caregivers would talk about the loss not of the person but of their spousal relationship.<sup>□</sup> Others articulated this disappearance of their spouse as an obscuring of the person behind a veil of Alzheimer’s. One man, in particular, often would talk of “my gal” still being “in there,” detailing moments when he saw “her” again. As families took up the discourse of loss with their daily lives, reworking loss of self to their terms, the threads of domestication start to become evident.

### *Person-Centered Care: The Moral Imperative of Family Caregiving*

The critique of the loss of self discourse centers around the link between memory and self. That link, and ultimately the stigma and marginalization it engenders, is what Post is calling attention to in his discussions of the hypercognitive society.<sup>22</sup> Critics tend to highlight the

---

<sup>21</sup> This is taken up more fully in chapter five.

<sup>22</sup> “A new ethics of dementia care will not accept the postulate of some that rationality and memory are the features that give rise to a person’s moral standing and protection. Too great an

narrowness of a rationalist view of selfhood and its cognitive seat, pointing to more capacious notions of self as inclusive of a person with dementia's continued humanity and, thus, right to care.<sup>23</sup> Scholars Steven Sabat and Rom Harre (1992), for example, articulate a difference between self 1 and self 2. Self 1, which they refer to as "one's personal identity," "is a structural or organizational feature of one's mentality. However the content of our thoughts and feelings may change, we are intact as persons if these are organized into one coherent whole" (445). They define self 2, on the other hand, as a "repertoire" of separate personae—there are multiple, socially-enacted selves 2.<sup>24</sup> They argue that Alzheimer's disease does not result in the loss of self 1, but rather the repertoire of selves 2 can be eroded through social interaction. As they write:

[T]he threatened disappearance of any self 2 is not directly linked to the progress of the disease. Rather, it is related to the behaviour of those who are regularly involved in the social life of the sufferer [sic]. ...[I]f there is a loss of the capacity to present an appropriate self 2, in many cases the fundamental cause is to be found not in the neurofibrillary tangles and senile plaques in the brains of the sufferers, but in the character of the social interactions and their interpretations that follow in the wake of the symptoms. (1992: 459-60).

---

emphasis placed on rationality and memory, arguably the cardinal values of modern technological societies, wrongly suggests an exclusion of people with dementia from the sphere of human dignity and respect. Rationalistic theories of moral standing, of who counts under the protective canopy of "DO no harm," discriminate against and often unacceptably dehumanize those among us who most need our moral commitment because they are most forgetful." (Post 2000a: 4)

<sup>23</sup> Of course, this suggests the question: Why is continued humanity necessary for care? Perhaps, rather than hypercognitive, as Post suggests, it is our hyper-anthropocentrism that needs to be questioned.

<sup>24</sup> They acknowledge Goffman's understanding of self as explicated in *The Presentation of Self in Everyday Life* (1959). While not cited, Mauss's (1985[1938]) notion of person also is clearly evident in the lineage of thought regarding the social relations that construct the person and personhood. He distinguishes between *personage* (the role), *personne* (person), and *moi* (self), articulating how social and psychological dimensions and understandings of personhood came into prominence across time.

Other scholars have turned to conceptualizations of a relational, socially-enacted self to combat the notion that the essential self of a person diagnosed with Alzheimer's can be lost through pathology alone (e.g., Bastings 2009, Herskovits 1995, Kitwood 1997, McLean 2007).<sup>25</sup>

Bridging the theoretical and the applied, British social psychologist Thomas Kitwood developed theory of dementia care based on the understanding of selves as relational (e.g., 1993, 1997). In doing so, he most fully articulated the ideals of person-centered care within the context of dementia. For Kitwood, the diminished personhood of the diagnosed person is the product of a malignant social psychology, by which he meant the “processes and interactions that tend to depersonalise a sufferer [*sic*] from dementia” (Baldwin and Capstick 2007: 37). This malignant social psychology comes from the lack of an understanding that personhood is inherently social and interdependent (Kitwood 1993). As he writes, “The strong word malignant signifies something very harmful, symptomatic of a care environment that is deeply damaging to personhood, possibly even undermining to physical well-being. ...Dementia in another person has the power to activate fears...[and] it is not surprising, then, if sensitivity has caused many people to shrink from such a prospect. ...The principal problem, then, is not that of changing people with dementia, or of ‘managing’ their behaviour; it is that of moving beyond our own anxieties and defenses, so that true meeting can occur, and life-giving relationships can grow” (Kitwood 1997: 46, 14).

In this context, family caregiving becomes a moral imperative. Post has called the family caregiver a “tribute to the human spirit” (2000: 25). Arthur Kleinman, who provided care for his

---

<sup>25</sup> Within anthropology, this shift has been termed the “personhood turn” or “personhood movement” (Cohen 2006; Leibing 2006, 2008).

wife after she was diagnosed with AD, has said caregiving is “at the core of what it means to be human” (2007: xi). This moral purity of the family caregiver, in many ways, is tied to her suffering. Kleinman has described the caregiver self as “divided,” split between the burdensome and the compassionate, the reaffirming (Kleinman 2010). As one engages in caregiving, she gains “a clearer picture of our divided condition as the human condition;” and once a caregiver recognizes and embraces this division, engaging in the often “demanding practice of caregiving,” she begins “to realize the fullness of our humanity, as well as the limits of our capability to transcend the self and develop the interpersonal moral potential of what it means to be human” (17-8). And Post writes:

Despite the limited support available to the family caregiver and those who fail to appreciate their often very isolated altruism, the caregiver usually carries on, sometimes to the point of exhaustion and stress-induced illness. The informal family caregiver is a stark contrast to a culture in which the value of life has been otherwise cheapened. (27)

The morality of the caregiver is one who gives to the point of self-sacrifice, even in the face of “limited support,” and comes to realize her humanity through that process.

### **Activity: The Link Between Alzheimer’s Disease and (In)dependence**

*“Next, its victims lose their independence, and then their very personalities. Finally, people with Alzheimer’s cannot even control their most basic bodily functions, such as speaking, walking, and eating.” (ASG 2009: 8)*

Activities, as discussed in the previous chapter, are the moments, places, and tasks where family members learn to see Alzheimer’s disease, locating it, as they do so, in their daily lives. While the range of activities through which AD emerges appears broader, initially including things like driving, working a computer, playing a sport, it quickly narrows to what becomes

known to families as “activities of daily living” (ADLs). The activities of ADLs quickly come to stand in for all activity as they are seen by family as composing the set of meaningful activities, the ones that matter for Alzheimer’s disease and family caregiving.

ADLs were originally developed in the mid-twentieth century in the US to, as the developers of one scale wrote, mark “the progressive loss of abilities and progressive increase in death rate” among older persons (Staff 1959: 55).<sup>26</sup> They were developed amid a growing a public health concern with chronic conditions that paralleled concerns about an aging population (Armstrong 2014; Katz 1983; Weisz 2014). Clinicians and researchers, interested not only in how people lost abilities but also how they might be rehabilitated, turned to the measurement of activities as a means of quantitatively tracking how both health and processes of aging affected a person’s functioning. Through ADLs, they looked to gain not just an evaluative perspective on people’s current health and functioning, but also a predictive perspective on how they would progress as they aged. Scales assumed a hierarchical ordering of functionality based on “degree of complexity required” (Lawton and Brody 1969). The hierarchy manifested along two dimensions: one, a person loses ability along the units of measurement (e.g., goes to the bathroom independently, requires assistance with going to the bathroom, uses a bedpan); and

---

<sup>26</sup> Multiple scales have been constructed over the past fifty years, often to assess functioning within a specific environment (e.g., hospital, long-term care facility, a person’s home) or for a specific condition (e.g., arthritis, heart disease, cognitive difficulties). They can include different items. For example, Katz and colleagues scale, the Index of Independence in Activities of Daily Living, uses feeding, bathing, dressing, going to the toilet, transferring, and continence (1963). Lawton and Brody, alternatively, adapted another scale for their use, which measured feeding, dressing, grooming (“neatness, hair, nails, hands, face, clothing” (1969: 180)), toileting, locomotion, and bathing.

two, the abilities themselves are gained or lost in order (e.g., bathing, dressing, going to the bathroom, transferring, continence, and feeding) (e.g., Katz et al 1963).

A series of specific activities, from feeding oneself to managing finances, that have been codified into biomedical scales, ADLs are used by clinicians like those in the Memory Clinic to measure a person's ability (or, more accurately, *inability*) to function in their day-to-day lives. The assessments are then applied widely: "Apart from diagnosis, the measurement of ADL performance allows the assessment of treatment effects, care-giver burden, the targeting of interventions and care packages and the elucidation of the link between cognition and everyday functional ability" (Bucks 1996: 113). Their broad application makes their underlying assumptions about activity and its connections to health, aging, self, and independence all the more problematic.

In the US imaginary, continued activity has long been considered critical to aging well. Activity theory, originally articulated in the 1950s, foregrounded the importance of continued pursuit of an active lifestyle as one ages. Activity, it was argued, kept one vital, maintaining physical and mental health, while "idleness, not aging, hasten[ed] illness and death" (Katz 2000: 138). The notion tied in well with ideas about retirement as a time of continued creativity and engagement. These links between maintained activity and health have been taken up in the promotion of successful aging, a model for aging well that has become increasingly popular among scholarly and lay audiences. While early discussions of successful aging focused on individual life satisfaction (Havighurst 1961, Neugarten 1972), physician John Rowe and psychologist Robert Kahn put forth what has arguably become the most influential conceptualization of successful aging (Rowe and Kahn 1987, 1997, 1998). According to their

definition, successful aging could be measured by one's success in three areas, "avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities" (1997: 439). The ties between aging, a particular version of health (as the absence of "disease and disability"), and activity are clear. Despite strong critique, the model's dominance continues, and its effects are felt in the context of Alzheimer's disease, where continued activity is widely regarded as a preventative measure against AD and as a means of slowing Alzheimer's progression.<sup>27</sup> Clinicians and other care providers promoted physical exercise, mental activity (e.g., crosswords, games), and social engagement for both those diagnosed and the non-diagnosed population, and several diagnosed people attributed their continued level of cognitive function to exercise.

As activity is wrapped up with ideologies of "permanent personhood" and continued health, it also comes to be seen as a measure of independence. ADLs, after all, are not just a measure of one's ability to complete a task, but an ability to do so *independently* (Lamb 2014). As Stephen Katz has written, "Thus, the aged subject becomes encased in a social matrix where moral, disciplinary conventions around activity, health, and independence appear to represent an idealized old age" (2000: 141). This focus, apparent across the literature of ADL development, is striking in the measurement scales for ADLs, a "graphic artifact" (Hull 2012) of clinical technology that requires family members to conceptualize and articulate moments of their lives in terms of activity, functionality, and embedded within these, independence. Typically, each

---

<sup>27</sup> Critiques of both activity theory and successful aging target the models' privileging of individual control, their lack of engagement with structural factors, their lack of diversity, their ageist and ableist assumptions, and their focus on a narrow understanding of "health" (e.g., Martinson and Berridge 2015; Katz 2000; Lamb 2014).

scale item consists of a category of activity and a number of descriptions, from which a person chooses one, that range from what is considered fully independent to fully dependent. For example, in the “Activities of Daily Living” section of the Memory Clinic’s patient-completed paperwork, the first activity listed is Eating, and the range of descriptions are: “Eats without assistance,” “Eats with minor assistance,” and “Requires extensive assistance for all meals.”

With their focus on independence and its loss, ADLs are necessarily relational in nature. The assumption is that a person’s decreased ability will correspond to their increased reliance upon others; a relationship of dependence is presupposed in the activities themselves. Health comes to be related to independence, in such a way that dependence comes to be a signifier of illness.<sup>28</sup> Assistive actions—when a family caregiver must provide instruction or repeat

---

<sup>28</sup> Disability studies has taken this privilege of “independence,” and the maintenance of its illusion, as a starting point of critique. As Lennard J. Davis (2002) writes, for example, in his elaboration of “dismodernism”:

“Enlightenment thought would have it that the human is a measurable quantity, that all men are created equal, and that each individual is paradoxically both the same and different. Or perhaps, as Kierkegaard put it, ‘the single individual is the particular that has its *telos* in the universal.’ In the past much of the paradoxical attitude toward citizens with disabilities arose from the conflict between notions of the equality of universal rights and the inequality of particular bodies.

“For all the hype of postmodern and deconstructive theory, these intellectual attempts made little or no impression on identity politics. Rather, those who pushed identity had very strong Enlightenment notions of the universal and the individual. The universal subject of postmodernism may be pierced and narrative-resistant but that subject was still whole, independent, unified, self-making, and capable. The dismodern era ushers in the concept that difference is what all of us have in common. That identity is not fixed but malleable. That technology is not separate but part of the body. That dependence, not individual independence, is the rule. There is no single clockmaker who made the uniform clock of the human body. The watchword of dismodernism could be: Form follows dysfunction” (26-7).

directions for his spouse to complete a task, for example, when she lays out clothes so her husband can dress—become signs of pathologized dependence.<sup>29</sup>

Eva Feder Kittay called dependency “inescapable in the life history of each individual” (1999: 29). Despite this, as she and many others have detailed, the predominant understanding of the self in the US imaginary is one of an independent, autonomous individual. The maintenance of this fiction of self depends upon a backstage where the dirty work of dependence can be carried out—a private, domestic sphere where those who engage in such devalued labor (women, racial and ethnic minorities, socioeconomically disadvantaged) can carry out their duties quietly and invisibly. The “frailties and incapacities” of chronic illness, aging, and life more generally crack the facade of the autonomous individual. Often, a family caregiver will work with her family member to maintain an appearance of independence; yet, as that becomes less possible, the dependent person will be whisked behind the closed doors of the family home, out of public sight.<sup>30</sup>

In considering activity, family caregiving and Alzheimer’s disease come together, articulating each other, at this point of dependency. At its base, caregiving involves doing something; it is an activity. More than anything, family members would talk about what they *did* as caregivers. When I asked her at what moments she felt like a caregiver, Joanne, whose

---

<sup>29</sup> As many others have written (e.g., Kittay 1999), dependence is an inevitable and unexceptional part of the human condition. Despite this, the daily moments of dependence we all experience are hidden behind and dispersed across multiple systems of labor and commodification, at the heart of which sits the family unit. By folding ‘independence’ into what it means to be a ‘fully functioning’ and ‘healthy’ human being and pathologizing the dependencies that become visible, people’s day-to-day dependencies continue to be masked.

<sup>30</sup> See Buch (2013) for a discussion of paid home health workers’ labor to maintain the appearance of independence among their clients, while they themselves—and the dependency they make evident—remain invisible.

husband Alan was living with AD, talked those times “when I am personally hands-on with Alan. Like getting dressed. Cutting his food.” Others talked about helping with getting ready in the morning or for bed, showering, brushing teeth. Sometimes they were taking on household tasks the other had previously done; invoking “traditional” gender roles, male caregivers would speak of taking on the tasks of cooking or cleaning, while female caregivers would say they had to take over the finances or yard work.

Joan Tronto, whose work *Moral Boundaries* (1993) is a foundational text on the ethics of care, has articulated four phases of care: caring about, taking care of, care-giving, and care-receiving (105-108). Across these phases, one draws ever closer to the object of that care, moving across scale from the large, abstract scale of “caring about” something, which involves a recognition that it requires care, to being that dependent, care-needing something. Caregiving, as she defines it, “involves the direct meeting of needs for care. It involves physical work, and almost always requires that care-givers come in contact with the objects of care” (107). Her examples are broadly drawn, ranging from delivering food to administering medication to doing laundry.

Most often, however, the activities of caregiving are more explicitly medical in nature. The Family Caregiver Alliance, a caregiving advocacy organization, for example, defines a caregiver as: “an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks” (<https://caregiver.org/selected-caregiver-statistics>, accessed November 2014). Caregiver advocate and researcher Carol Levine writes of caregiving as a “job, which may include providing personal care, carrying out medical procedures, managing a household, and interacting with the

formal health care and social service systems on another's behalf" (2004: 2). Richard Schulz, a social psychologist who has written extensively on family caregiving, writes of caregiving as "involv[ing] a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting" (2004: 240).

The language of "tasks" is common across the literature. *The 36-Hour Day*, considered *the* family caregiver manual for people living with AD, is structured around what family members can do, as caregivers, to help with the challenges such as increased "behavioral symptoms," decreased ability to maintain "independent living," problems of "daily care," and increased "medical problems," as well as taking care of one's self and planning for the future (2006[1981]). As they write in the opening, "This book is designed to help you with...the tasks of day-to-day management of a chronically ill family member" (5). Often, the discussions that follow are a blend of advice on how to think and feel about life with Alzheimer disease (what sociologist Javier Gubrium (1986) has called cognitive and affective rules) and suggestions about what to *do*, about tasks one can take on, as one encounters different situations. While these descriptions encompass a range of activities—some seemingly more, others seemingly less medical—they all acquire a patina of medicalization. Daily activities become an act of caregiving when one person requires assistance to complete them, such that when I was conducting fieldwork in the homes of people who had been diagnosed with early-onset AD and their families, a meal cooked for all of us would become an act of caregiving toward the person diagnosed but not toward myself.

## The Temporality of Decline

*“Alzheimer’s disease is not just a little memory loss. It eventually kills you, but not before it takes everything away...It means the loss of anything and everything you have ever known.”*

*“Just imagine the tragedy of watching your loved one, the light of your life, slowly disappearing day by day.” (AA 2011: 4, 8)*

The temporality of Alzheimer’s disease is inescapable. The movement through time structures conceptualizations of Alzheimer’s, even more than notions of memory. And the movement that characterizes Alzheimer’s disease is, without exception, a slow, inevitable decline.<sup>31</sup> This is the prognosis of Alzheimer’s disease within which, once diagnosed, one lives (Jain 2007, 2013); it is what one can anticipate (Adams, Murphy, and Clarke 2009). The protracted decline comes to structure not just the temporality of the condition but all time within the home.

In diagnostic criteria and public imagination, Alzheimer’s disease is marked by a steady downward trajectory of a person’s cognitive ability. Movement along that trajectory is how the condition is known; that movement is tracked and measured as an indication of its progression. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR) describes the course of Dementia of the Alzheimer’s Type as “characterized by *gradual onset* and *continuing cognitive decline*” (APA 2000: XX, emphasis added). The losses of memory and cognition themselves index the temporality of decline, its past and present. Loss is, by nature, diachronic: Both can only be considered lost when measured against a prior instantiation, and in the context of AD,

---

<sup>31</sup> Taylor writes of this: “They are seeking a landmark by which to gauge the stage of my mother’s progress along what everyone understands to be a one-way journey downhill.” (2008: 315).

that loss is then projected into the future. Loss will continue without hope of remission, and a continual downward trajectory becomes evidence of the progression of Alzheimer's.<sup>32</sup>

Decline, and its correlate progression, often are described by clinicians and in the many caregiver guides as movement through a temporally-ordered series of stages. Clinicians in the Memory Clinic and the instructive materials they provided to families and care professionals, for example, most frequently described three stages: early or mild, middle or moderate, and late or severe. A person's movement across these stages is marked in a worsening presentation of symptoms. In the guide clinicians provided to family members of newly diagnosed persons, stages were described as beginning with and progressing onward from "mild AD," in which

people often have some memory loss and small changes in their personality. They may have trouble remembering recent events or the names of familiar people or things. They may no longer be able to solve simple math problems or balance a checkbook. People with mild AD also slowly lose the ability to plan and organize. For example, they may have trouble making a grocery list and finding items in the store. (nd 5)

The family caregiver guide's narrative traces the symptomatic domains where Alzheimer's typically first becomes noticeable to the person or her family, close friends, and colleagues—memory, personality, and familiar activities of daily living (ADLs) associated with executive functioning. The language of decline, even in this first stage, is already present, as people with mild AD have memory *loss* and *changes* and are *no longer* able to do things as they *lose* abilities. This marking against a former ability is what makes Alzheimer's visible. Across the stages, areas where loss was noted earlier "worsen" and new areas of decline (from a prediagnosed baseline) become apparent. As a person moves into the middle or moderate stage,

---

<sup>32</sup> Decline is linked to the progression of AD in the oft-used phrase "progressive memory loss".

the guide tells its reader, “memory loss and confusion become more obvious” and “personality changes can become more serious” (6). In addition, changes in continence, judgment, and sleep can become apparent. In the final stage, the person’s abilities are described as almost entirely lacking: they “often need help with all their daily needs”, “may not be able to walk or sit up without help”, “may not be able to talk and often cannot recognize family members,” and “may have trouble swallowing and refuse to eat.”<sup>33</sup>

Families themselves talk of themselves and their lives in relation to the temporality of inevitable decline. One informant, William, who was particularly reflexive about his own experience, wrote in a piece on hope:

[T]he one thing that I know is that no matter how much the medicines hold off the encroaching plaques and tangles that are slowly scrambling my brain, ultimately the disease will gradually take me away, if something else doesn’t first. And probably I will end my journey earlier than I had hoped for. My grandmother lived to age 91, and my father is now the same age. I, who am now 66, will probably not live anywhere near that long.

Five years later, he wrote in another piece, “Almost seven years later I have accepted [the diagnosis] and the restrictions that have come with it, but not without regret. I can sense now that I am slowly fading away (as slowly as I can muster and my meds can facilitate).” Gradual, but certain “fading” fills the descriptions. Frequently family caregivers and those diagnosed would respond to questions about how they were doing in terms of a diagnosed person’s current ability and how it has noticeably changed. Bridget, whose husband Alex had been diagnosed, told me when we talked in October 2011 that she saw him “declining. He’s declining. You try and do

---

<sup>33</sup> This last, a refusal to eat, is a notable anomaly in the list, as it is an agentic moment for the person diagnosed. That moment, however, as discussed further in Chapter 3, can only be read in terms of the disease’s progression, not an actual agentic action on the part of the person.

what you can do, with the clinical trial and all that. And if something helps out, that's great. But in my mind, this is going to decrease. I need to wrap my mind around that." This way of framing the conversation, while obviously to some extent primed by our interview setting, became pervasive for talking across setting about not only Alzheimer's but their lives and who they were.

The inevitability of decline was, perhaps, most pronounced when families tried *not* to talk about it. One evening, I was at a dinner with Susan, Joanne, Shawna, and a fourth woman Sandy, whose husbands all had been diagnosed and who had met through the Memory Clinic support group. The conversation turned, at one point, to how they navigated trying to answer the question of how things were going. Joanne said, "I appreciate it when they ask me, 'How's he doing? How are you doing?'" You know, or whatever. But I don't want it." All four, even though frustrated by their friends' questions and responses, recognized that friends and family. Sandy said, "They don't know what to say. It's really just small talk, just trying to make conversation. They want to show their concern, acknowledge that we have an issue." Shawna talked about friends asking at work, where Jonathon used to work as well, "Everybody loved Jonathon; everybody knew Jonathon. So everyday, I get, 'How's Jonathon doing?'" "What're you going to say? 'Well, he's declining rapidly, and um...'," Joanne quipped darkly. "You don't wanna start a conversation like that either," Sandy said. Shawna answered, "Most of the time I say, 'He's doing as well as can be expected.'" Decline, in their telling, is the only frame for talking about their lives. The only way to avoid talking in terms of decline, as the group understands it, is to deflect conversation about their lives entirely. "People ask how he is," Susan said, "and I say, 'Oh he's fine. He's doing great.'"

Even in the writing of this dissertation, I find myself at a loss for the language to work around the temporality as only decline. The language of loss pervades discussions of AD. How to talk about memory loss, or the progression of Alzheimer's, or a person's increased inability to navigate stairs without invoking this decline. "Change" seems so bland and inaccurate. It's not that I necessarily want to avoid talking about inevitable decline and progression—given the structuring power of this temporality, I find a discussion of it front and center. Rather, the rub is that, if I—or more, those with whom I worked—wanted to do so, we found ourselves trapped within the narrative of certain loss.

Decline, loss, and a horizon of death are temporalities that structure many medical and medicalized conditions—and dominant understandings in the US of life itself, for that matter. As this temporal understanding comes together with the loss of self discourse, they weave a tight, harrowing narrative, one which families often take up, even as they alter it to focus on relations, rather than selves. The inevitable and unending quality of the decline, a decline that irreversibly dissolves family-making endeavors, are what seemed to make it so challenging for the families living with AD. Families come to orient to the decline itself, a kind of chronic terminality.

### **The Logic of the Coming Cure**

*"We are going to pay for Alzheimer's one way or the other. The consequences of doing nothing will be continuing to pay for caring — and we should ensure more effective care for those with this devastating disease. But if we commit now to **curing** — to fund research that leads to a breakthrough — we can save billions of dollars. A commitment today to innovation, to finding a cure, will yield the savings of tomorrow." (AA 2011: 10)*

Since Alzheimer's re-emergence in the 1970s, a persistent national lobbying effort to fund basic and clinical research on Alzheimer's disease has developed its discourse within the

logic of a coming cure. As activists and researchers have successfully propagated their message of cure over the past forty years, the logic of the coming cure has only solidified. While such a response seems almost natural in light of the overwhelming narrative of medical triumphalism in the US, the dominance of a logic of coming cure was not a given, but rather was carefully crafted. It is a logic that conceptualizes the condition of dementia as a disease, Alzheimer's disease. It prompts a medicalized relation of intervention and proffers cure as the only viable action a person—whether policymaker, researcher, clinician, family member, or person diagnosed—can take. Any understanding of care—what that might mean; what kind of labor, relations, practices, or morality it might involve; what sort of effect it might have and how that effect is measured—comes to be articulated in the public's discourse within the shadow of the logic of a coming cure.

The distinction between the logics of cure and care in the context of dementia can be traced back, at least, to the consolidation of the concept of Alzheimer's disease as both the iconic representation of all dementias and that which the cure is supposed to eradicate (Fox 1989, Gubrium 1986, Ballenger 2006). The disease category of Alzheimer's disease, in its current form, both separated the condition from so-called normal aging and operated as an umbrella to cover all dementias. The result of a political effort coordinated between the biomedical community, the National Institute of Aging (NIA), the Alzheimer's Disease and Related Dementias Association (ADRDA; now, tellingly, the Alzheimer's Association), the media, and families living with dementia, the unified concept of Alzheimer's disease "was central in focusing the interests and activities of a variety of social collectivities with differing but related interests in that it served as a legitimate framework around which collective action could be

mobilized and policies to address the problem of Alzheimer's disease could be developed” (Fox 1989, 59-60). Around a single disease, action became possible.

Highlighting the dominance of a logic of cure, scholars have clearly traced conflicts around Alzheimer’s disease’s unification as a disease concept, in particular across the development of the ADRDA, as an organization comprising both biomedical researchers and family advocates. A single, specific disease, proponents of the unified concept argued, was something around which awareness could be raised and support could be rallied. Yet, families and their advocates argued, limiting advocacy efforts around a single disease eliminated the possibility of support for other families who were dealing with different conditions: “If increasing support for caregivers was the primary goal of the association, the logical course would be to create a broader constituency of people affected by the many diseases which would have benefited from the same policies” (Ballenger 2006, 118). Such increased support, however, was not the primary goal of the ADRDA’s biomedically-minded members, who first and foremost sought increased funding for research programming. And such funding was most readily allocated to research targeted at specific diseases.<sup>34</sup> Given the legitimacy and authority of biomedical expertise, increasing research funding became a leading priority for the Association, which since its inception has largely shaped the public debates surrounding dementia and how to fight it, and its effects soon became clear throughout lobbying efforts.<sup>35</sup>

---

<sup>34</sup> The most strident comparisons were made between the search for a cure for Alzheimer’s disease and for polio (Ballenger 2006: 122-4). See also chapter 4 here.

<sup>35</sup> Ballenger notes, and I agree, that the bias in the rhetoric is likely an unintentional effect. He writes: “It is possible that the leadership or the rank and file of the Alzheimer's Association (or both) consciously put funding for research ahead of support for caregiving, but I have found nothing in the association's public records (annual reports, newsletters, press releases, etc.) to suggest this. Moreover, the association's commitment to winning support for caregivers seems

Consolidated behind a unified Alzheimer’s disease concept and a faith in the power of medical science, activists set about lobbying to increase research funding to combat the disease, and they did so by articulating a framework wherein the only viable action to take against dementia was to cure it. The economic and political milieu of the late 1970s and early 1980s provided the ideal environment for the rhetorical framing of activists. Within the political environment of small government and state retrenchment in the 1980s, advocates’ narrative fed into politicians’ desire to strip down social welfare programs to, and often beyond, their bare essentials (Ballenger 2006, Chauffen et al. 2012). Economic arguments that set the dollars for care against the dollars spent on cure held powerful sway for those allocating funds: As the ADRDA’s first annual report stated it: “Our nation still spends 800 times more to care for our nearly three million Alzheimer’s victims than it allocates for research” (quoted in Ballenger, 120). The post-Cold War fetishization of the nuclear family—and the work of caregiving it concealed from public eye (and, notably, pocketbook)—only added to the notion that the most heroic, collective role government could take would be to invest in the search for a cure (Chauffen et al. 2012, 792).

The political implications of the logic and the attendant narrative framework have been a prioritization of funding for research, with little consideration for infrastructure to care for those living with dementia. Historian Jesse Ballenger has eloquently detailed the rhetorical framing

---

hard to question. For example, the association was clearly at the forefront of efforts in the late 1980s to get federally supported long-term care insurance on the agenda of national politics. Nonetheless, implicit in the lobbying strategy the association adopted was a trade-off—albeit unacknowledged and unexamined—between support for research and support for caregiving” (2006: 118). And that trade-off has had critical implications for how families understand and live with Alzheimer’s disease.

and how that framing created a “trade-off—albeit unacknowledged and unexamined—between support for research and support for caregiving” (2006: 118, see Chapter 5, esp. 118-128).

Activists invoked depictions of people with Alzheimer’s disease in an attempt to “giv[e] the disease a human face,” which “provided an emotional appeal that helped raise the moral stakes in battling the disease above the arcana of federal budget policy” (128). They articulated Alzheimer’s disease as “the disease of the century,” detailing the burden of a so-called aging crisis on an already strained economy and healthcare system.

Within this discourse, caring for those with Alzheimer’s disease—and the costs associated with doing so—necessarily, if unintentionally, became the evil that scientific progress through research was intended to avoid. Activists

forged a link between the costs of caregiving and the need for research which implicitly (and sometimes explicitly) undermined the plausibility of arguments that could be made for major social policy initiatives to address the problems of caregivers. In making the case for research funding, Alzheimer’s advocates emphasized the tremendous economic burden the disease placed on society...costs that would dramatically increase if a treatment or cure for the disease was not found. (119)

Care, articulated as an intervention that cost without effect, became a foil to cure’s action, one destined to fail—and also drag down the people and the nation—under the coming crushing weight of Alzheimer’s oppression. Yet, the cure is not here; it is only coming.

## **Conclusion**

In 2010, Canadian graphic artist Sarah Leavitt published a autobiographical memoir entitled *Tangles*.<sup>36</sup> The narrative traces her family’s journey with her mother Midge’s early-onset

---

<sup>36</sup> The memoir subsequently was published in 2012 in the United States.

Alzheimer disease, moving from early signs of confusion through Midge's diagnosis and subsequent story. The graphic memoir provides a complement to *Still Alice* because Leavitt's depiction of her mother's Alzheimer's disease through the graphic medium reveals the ways that Alzheimer's comes to be located in the daily lives of family, offering a narrative dense with domestic detail. About halfway through her memoir, in a section called "Food," Leavitt begins with two frames sketching the kind of cook Midge had always been—healthy, using local ingredients often from her own garden—and how she and her sister had grown to appreciate this homemade cooking over the years. "When Mom got sick," she writes in a third frame, containing only words, "everything changed." She shows the reader how Midge was no longer able to garden or cook. Across a small frame with a hastily drawn steaming pot, kettle of boiling water, and a knife, dripping ominously, she writes, "Tools became weapons. Things got ruined." Rob, Midge's husband, Leavitt's father, took over cooking, but whether from depression or lack of hunger, she writes, "he started making a lot of pasta with sauce from a jar. The shift in the centrality of food and eating for the family disturbs Leavitt; she works to reinvigorate her parents' interest in and attention to meals and mealtime, growing increasingly angry as her attempts are thwarted by Rob and Midge, Leavitt's sister, and Midge's sisters who help to care. In a pivotal frame, Leavitt writes over a picture depicting Midge as angry, refusing eggs her less-than-culinary sister has burned: "The kitchen was like a billboard with huge letters saying, ALZHEIMER'S LIVES HERE! YOUR MOTHER IS GONE."

This chapter has articulated the ideologies and understandings of Alzheimer's disease and family caregiving that make such a frame, positing Alzheimer's usurpation of Leavitt's mother, possible. I have argued that, through the dominant narrative of AD, a focus on memory and

activity, and the divergent temporalities of decline and the coming cure, both Alzheimer's and family caregiving come to have particular shapes as sociohistorical formations within an ecological niche. The remainder of the dissertation traces out the effects of these formations on family's daily lives, both how they constrain families and how families rework them in novel ways as they go about projects of family-making.

### **Chapter 3 — The Consequences of Doing Nothing: The Non-Action of Care in the Logic of the Coming Cure**

#### **“The anger and frustration of not being able to do anything”**

In May of 2011, an Alzheimer’s Disease Center (ADC) in the midwestern United States held its annual all-day conference for medical and care professionals, researchers, and families. Each year, the organizers structured the event, intended to highlight ongoing research in which the Center was engaged, around several presentations by ADC researchers and staff members, punctuated by a late morning research presentation by an outside speaker and an afternoon family-oriented presentation and panel discussion. The organization of the event itself—the separation of biomedically- and family-focused presentations, for example, and the prominence of the research sessions—highlighted how people living with Alzheimer’s disease—both those diagnosed and their family caregivers—were seemingly central yet actually marginalized within the logic of a coming cure. And this relationship between biomedicine, Alzheimer’s, and family caregiving would only become more evident across the day.

Entering the large, sunny conference room that morning, I was greeted by rows of chairs facing three large screens that projected a repeating series of PowerPoint slides that included bullet-pointed facts about Alzheimer’s disease, the Center and what it had accomplished since its inception, and the conference, as well as tips for caregivers about how to be a “healthy caregiver” (e.g., get help, “give yourself credit, not guilt”, take care of yourself) and ways for others to help them (e.g., rent a movie for the family and offer to return it). Several seats were taken by family members, older, dressed casually, and usually standing alone or in pairs. The researchers, clinicians, social workers, and administrators who composed the ADC staff occupied

far more, spreading across the front rows, talking in clumps, dressed in business attire or lab coats.

The event opened with an introduction by the Center’s director, followed by a researcher from a west coast Alzheimer’s Disease Center, who presented on cognitive functioning among people over 85 (the “oldest-old”), highlighting, among other things, the distinctions researchers have been tracking between those who eventually have dementia diagnoses and those who do not and strategies for “aging successfully.” During the question-and-answer that followed, questions focused on ways to stave off the creep of cognitive decline: Does caffeine help? Should we be taking aspirin for its anti-inflammatory properties? What is the relationship between smoking and Alzheimer’s? How does cognitive reserve work?<sup>1</sup> How does a person’s socioeconomic status and level of education affect their cognitive functioning and the chances for successful aging? The general theme: How do we protect the person who doesn’t yet have Alzheimer’s?

Lunch was organized around a poster presentation session, where researchers from the ADC presented their work. Thirty-four of the forty-three research posters presented work on the basic science and clinical research done at the Center. Of the remaining nine, one was on the effects of reiki treatments, given by care professionals, to people diagnosed with dementia; one, a

---

<sup>1</sup> Theories of cognitive reserve posit that the brain can actively work around damage it sustains: “[T]he cognitive reserve (CR) model suggests that the brain actively attempts to cope with brain damage by using pre-existing cognitive processing approaches or by enlisting compensatory approaches. ... Thus neural reserve could take the form of using brain networks or cognitive paradigms that are more efficient or flexible and thus less susceptible to disruption. ... In contrast, neural compensation refers to adopting new, compensatory brain networks or paradigms because pathology has impacted those that are normally used in no [sic] affected individuals. ... A straightforward example of this is in Alzheimer’s disease, where both imaging and post-mortem studies have suggested that in individuals with the same amount of brain pathology, those with higher levels of reserve show less severe clinical dementia” (Stern 2013: 1-2). For a critique of cognitive reserve theory, see Satz, Cole, Hardy, and Rassovsky (2011).

mindfulness intervention for people diagnosed with AD and their caregivers; and one, outlining the recruitment and outreach conducted, with the remaining six detailing those outreach efforts. Families walked through the posters, occasionally asking questions of the presenters, but mostly sitting together and eating.

For the afternoon session, the dynamic changed. More families had arrived during lunch and now clearly outnumbered the researchers, most of whom, other than senior Center personnel, had left. The session began with a presentation by Barry Petersen, a long-time CBS correspondent whose wife Jan had been diagnosed a few years before with early-onset Alzheimer's. To provide some background, Petersen began with a short video segment on his and Jan's life post-diagnosis that he had put together for CBS This Morning, after which he discussed difficulties he perceived for Jan as the condition progressed, the challenges of providing care, his struggles with depression and suicide, and the importance of raising awareness about Alzheimer's disease. As his talk concluded, he was about to open it up for questions when he paused, looked down, and then began speaking off script in a voice whose even tone barely belied that which roiled beneath:

You know, if you really sense an undercurrent of anger here, it's anger at the disease. It's the anger and frustration of not being able to...do anything? To help. To stand there and watch Jan fade away. And, let me just share one other thing. About Alzheimer's. It's the only disease that we deal with alone. ...[W]hen you have cancer, diabetes, arthritis, name ten more diseases, I don't know, you go to a doctor and you get a team. You have cancer, you get an oncologist, you get a therapist, you get a doctor, you get rehab, but most of all you get the person who has the disease who's a part of the team. You know what you get with Alzheimer's? You get a neurologist. Once a year, you go see the neurologist, who says to you, "She's slipped this much farther." That's what you get.

As I listened, I noted his language: “not being able to do anything.” The amount of labor that goes into family caregiving is increasingly discussed in popular media (e.g., Gross 2008).<sup>2</sup> I often heard family members speak of an inability to do anything, and given the amount of family-making and caregiving work that I saw both those diagnosed and family caregivers do, in fact, do, I was always surprised by how quickly they rendered themselves non-acting subjects.

After his presentation, he opened the floor for questions. The first question was from a woman seated near the front of the audience. Giving voice to a lack of agency many caregivers describe, she talked about a friend who felt, after her husband’s diagnosis, that “there was nothing to do.” As she put it, “She said there was a total disconnect between the doctor’s office and what this woman was to do,” and she asked Petersen what steps a family could take after diagnosis. Repeating the question, he answered, “The answer is: There’s nothing to do. (0.5) I mean there’s really nothing to do.” He talked about how, in his estimation, “[M]ost doctors don’t want to diagnose Alzheimer’s. Because doctors are not trained to deal with diseases they can’t cure. Doctors sometimes can be as brilliant at denial as I was. Because they don’t want to go down that road. It’s not anything evil. It’s against everything that they’re trained to do.” He went on:

So, when we got the diagnosis, (0.5) went to see a neurologist who said, Here’s what you can do: You can take Aricept. You can take Namenda. You can take Razadyne. And you can take Exelon.<sup>3</sup> And I think that pretty much covers the

---

<sup>2</sup> The labor of caregiving—the economic value, as it is rendered (e.g., Arno 1999)—is known and deployed by activists, as well. However, as discussed in the previous chapter, it becomes data for an argument about the deleterious impact of caregiving, rather than one to garner support for it.

<sup>3</sup> A clinician’s view of treatment efficacy often reflects their understanding of the trajectories of AD. One clinician I interviewed, for example, described AD as a “treatable disease now,” one that is addressed with a “dual therapy with a cholinesterase inhibitor, which are drugs like donepezil and galantamine and rivastigmine, in conjunction with Namenda. ... That’s pretty

range of medications, right? ...And the doctor made clear—and it's true—we have no medication to fight the disease. All of these medications treat the symptoms. And they help; they'll beat back the symptoms for a while. Jan went through Aricept in about 18 months—that may be longer even than most people. Razidyne? [makes a dismissive, raspberry sound] Three months. Cause it arcs, and then it's finished. But it did give Jan a great sense of fighting back. And I think (1.5) maybe that helped? Maybe it just contributed more to our denial. I don't know.

This chapter is about how families understand their ability to continue to act upon the world as they learn to live with Alzheimer's disease. Petersen's emphatic insistence that there's "nothing to do" gives voice to a core tension at the center of the chapter, one noted by people throughout my fieldwork: Although family members—both people diagnosed with Alzheimer's and their family caregivers—do an enormous amount of work to maintain their daily lives with Alzheimer's, that labor often is not recognized as legitimate action. In part, the devaluing of families' actions is about specific actions and activities recognized as family caregiving and the perception of their inefficacy to effect meaningful change within the logic of a coming cure.

---

much the standard of care." The first three are approved for use with patients experiencing mild, moderate, or severe dementia. One will be chosen—in the Memory Clinic, donepezil (brand name, Aricept) most often is selected first—and started upon diagnosis. □ Cholinesterase inhibitors work to maintain the brain's levels of acetylcholine, a critical neurotransmitter in certain function of learning, attention, and memory. These drugs slow the breakdown of the neurotransmitter. However, they neither stop its decay nor produce acetylcholine, and they tend to be effective for limited period of time (six months to a year) in about half the people who use them. The latter medication, memantine (brand name, Namenda), works to regulate another neurotransmitter, glutamate, which also is involved in processes of learning and memory but the overproduction of which can be toxic to the brain. It is approved for moderate to severe dementia and often is started as a person's presentation of symptoms worsens. As with cholinesterase inhibitors, rather than stopping the overproduction of glutamate, memantine helps to regulate it in order to slow the harmful process for a time; however, dementia continues even with its use. For this clinician, the ability to slow the trajectory of the condition constituted an ability to treat it. Treatment did not necessarily entail a reversal of the trajectories of disease progression and cognitive decline. Slowing these processes was felt to increase a person's continued ability to function in his daily life, improving the quality of that life.

Structured by the logic of a coming cure, as people come to see themselves within a caregiving relationship, they understand the value of caregiving in terms of its inability to alter the trajectory of the condition, to stop the decline of Alzheimer's, in short, to provide a cure. However, it also is about the labor of family, the continual familial maintenance and reproduction that both the diagnosed person and her family members undertake, and how much of that labor is rendered invisible as it is considered "normal household life."

The work of family is marginalized as non-action as it is reframed as caregiving within the logic of the coming cure. Non-action, different from a lack of action that characterizes something like inaction, is ineffectual, even though it might be extensive. In the chapter, I demonstrate that non-action comes to characterize the lives and actions of both people diagnosed with Alzheimer's and their family caregivers. Diagnosed persons, having become "people with AD" as people who interact with them quickly learn to evaluate their actions through the lens of that diagnosis, are left with little agency to act upon or in the world. The actions which constitute their daily lives are as susceptible to these erasing medicalized interpretations as any other. The actions of family caregivers are subjected to a different, but no less delegitimizing treatment. The actions that are not relegated to the invisibility of normal domestic labor and are acknowledged as caregiving still are not recognized as legitimate because they are not seen to affect the overall trajectory of the condition.

### **Action and Non-Action in the Logic of the Coming Cure**

*We are going to pay for Alzheimer's one way or the other. The consequences of doing nothing will be continuing to pay for caring (Alzheimer's Association 2011: 10)*

As discussed in chapter two, advocates of research for an Alzheimer's cure have deployed a logic that structures what it means to live with Alzheimer's for both those diagnosed and family caregivers. Little has changed in the narrative framework of Alzheimer's activism since its early incarnations, and its call for funding in the face of an otherwise unstoppable medical condition has become commonplace among disease specific activist efforts. Across its many deployments, the framework has brought into being various actors (e.g., Alzheimer's disease, researchers, activists, people diagnosed with the condition, their families), casting some as able to act and others as capable only of non-action.

Crafted within a metaphor of war that is frequently deployed within narratives of medical triumphalism (Sontag 2013[1977/1988]), the narrative is written as a battle between the forces of disease and medical science. The primary actor is Alzheimer's disease itself, which is described as the ultimate enemy, threatening people, their families, and the nation. The language of enemy Alzheimer's is active, as it necessarily must be in order to motivate a response. To be something that "we can overcome," Alzheimer's needs to actively encroach. Alzheimer's disease strips memories, takes a toll on families, clouds a nation's future; it devastates and it costs. "Our" only "real" hope (a pronominal choice discussed further in the next chapter), the discourse informs, is in medical science, which promises a cure that will save lives and dollars. As a "genuine and tangible hope," a cure can act against the enemy of disease. In turn, the medical and research communities who facilitate the search for a cure emerge as actors: They will act to find a cure that, then, will act to overcome Alzheimer's disease, to yield the promised savings.

In contrast, those living with Alzheimer's disease are cast as ineffectual participants in the narrative, upon whom the disease acts and whose interventions have no effect. People

diagnosed with the condition are its acted-upon victims: they are the recipients of care who cannot act; they can only succumb to Alzheimer's, increasingly cared for as they disappear. Families, too, are rendered in language without active potential: They are forced to stand by and watch as their loved ones are lost to the disease's onslaught. They engage in acts of caregiving, which are continually represented only as burden, toll, and cost for both individuals and the nation.

As a disease takes shape within the narrative, the parameters of possibility are determined. Research directed toward a cure can "lead to a breakthrough," while "continuing to pay for caring" will be "the consequences of doing nothing." As cure and care are dichotomized in this way, the various players are set in relation to each other and granted differing degrees of agency to act. In contrast to the agents of scientific research and Alzheimer's disease itself, people diagnosed with AD, their families, and the work they do have been marginalized as they are cast as non-agentive and ineffectual.

The efforts of people diagnosed with Alzheimer's disease and their families rarely are made invisible; yet, frequently they are dismissed as having little value. Their actions are not valued—by policymakers, activists, researchers, the general public, and often themselves—as meaningful because they are perceived as ineffectual against Alzheimer's disease itself. Their daily lives are written only as "care," and within a logic of cure constituted largely by activist discourse, since actions of care do not contribute to the search for a cure, they, by definition, cannot work against the disease. They "do nothing." They can only be non-actions. Non-action is different than no action; "doing nothing" is different than not doing anything. It also stands in contrast to passivity, with the latter's implications of only being acted upon. The subject is

acting, but to little effect. Rather than concerning the ability to act, to *do things*, non-action is about the ability to effect change that is perceived as meaningful through that action.

Meaningful action has come to be defined in the public's imagination by an action's effect on the trajectories of cognitive decline, national crisis, and eventual cure that the logic of the coming cure has set in motion. In this paradigm, meaningful action would "modify the disease" by striking at the cause and thereby reversing the disease's inevitable cognitive decline.<sup>4</sup> Cure, when one is discovered, will be able to do this. The actions of families can only attend to the consequences of Alzheimer's disease, the changes to a person and her ability to relate to the world. Those who are caregivers are unable to address the disease's cause; the pathology will continue to progress, and the person will continue to decline. Those who are diagnosed fall prey to that progress, unable to continue acting upon the world. "No action"—no *meaningful* action—can occur.

Families also fail on a population level, ineffective against the pending epidemic that the Alzheimer's activist narrative continually projects. It is this impending trajectory that "clouds our Nation's future." A 2010 Alzheimer Association publication entitled, "Changing the Trajectory of Alzheimer's Disease: A National Imperative," charts this trajectory of the disease as one that will result in a crushing increase in number of people with AD, a shifting, rising percentage of those people who are in a severe stage (implicating the first trajectory), and a stunning increase in care costs "from \$172 billion in 2010 to \$1.08 trillion in 2050" (4). The negative value of care, of families' lives, is explicitly called out: care can only cost, while cure can save the nation this

---

<sup>4</sup> Of course, as discussed in the next chapter, this is not exactly true, as the search for a "cure" has come to focus on the search for preventative treatment, which will stop the trajectory before it starts but have little effect on those already started along the journey of Alzheimer's disease.

economic blow.<sup>5</sup> The motivation to act, of course, is to act in service of this cure, the search for which constitutes the arc of the final trajectory. This trajectory takes on a prophetic temporality, as the cure is sure to found, but when the discovery will happen is something no one knows. Such uncertainty creates, as Jane Guyer has written of Christians awaiting the second coming of their Messiah, an “enduring attitude of expectant waiting” (Guyer 2007: 414). And it is the uncertain endpoint of this search that gives rise to a logic of the *coming* cure, rather than simply a logic of cure.

### **The Non-Action of Diagnosed People**

Those diagnosed with Alzheimer’s disease are rendered non-actors as Alzheimer’s itself becomes a more powerful actor. Once a person has been diagnosed with AD, her ability to act upon the world is seen as compromised by those who interact with her, increasingly obscured by the active Alzheimer’s disease that dominates national discourse. As the people with whom I worked underwent cognitive changes, others began to talk about their intentions and actions through the lens of their diagnosis. Early on in my research, I sat in a clinical research trial appointment with a man who had been diagnosed with early-onset AD and his wife. As he took off his shirt in order to put on a hospital gown for the physical examination, his wife pointed to his pants, raising her eyebrow: He had missed a belt loop. As she turned her attention back to her

---

<sup>5</sup> In addition, important for the discussion, this projection of the disease and its effects upon a nation shifts Alzheimer’s disease from a condition of individual brain pathology to one of a population’s potential demise. It is the scale of the projected epidemic, as well as its potential to strike “all of us,” that creates a “sense of urgency” for activists; without it, according to the rhetoric of Comer and many activists, the motivation to act now dissipates. Yet, as they create urgency in the future, they enervate the present, the time in which people living with the condition must grapple with its consequences.

husband and the clinician, I subtly reached down to check my own pants. Later, she recounted the moment to some friends who also were family caregivers, and the group had a conversation about their spouses' abilities to manage belts and the progression of their Alzheimer's.

As families interacted with clinicians, attended support group meetings, and went about their daily lives, they become more finely calibrated to see Alzheimer's disease in a diagnosed person's actions.<sup>6</sup> When diagnosed people acted upon the world, those actions increasingly were read as the result of Alzheimer's disease. Sometimes, as above, potentially innocuous actions were reinterpreted as symptoms, either in the present or the past. Family members came to have well-articulated narratives of early "missed symptoms" that they previously had ignored or attributed to other causes, such as stress or absent-mindedness. They talked about lost jobs, poorly made meals, forgotten routes. One wife recounted a story of how her husband literally painted himself into the corner of their garage as early evidence of a growing cognitive difficulty with planning and making choices. Another, during an interview, pulled out a deck of cards that her husband had marked with a Post-It note, writing "5 of spades is missing." Her husband had lost his job prior to his diagnosis, and she felt this was evidence of how Alzheimer's disease was affecting him at that point, as he became sidetracked in tasks such counting the cards within their decks. Other possible causes, choices, aspects of a person's personality subsumed within the narrative of an active Alzheimer's disease.

---

<sup>6</sup> Family caregivers, especially those who live with the diagnosed person, are the agents of much of this attenuation of diagnosed people's ability to act because of the time they spend with those diagnosed, their increasingly fine-tuned calibration, and the increasing isolation from extended family and friend networks that many families report experiencing.

Even when diagnosed people's actions are not seen as symptoms, per se, they still are moments when Alzheimer's becomes increasingly visible, read in terms of loss, dependency, and compensation. One woman with whom I worked would talk about how her husband had started to walk a step or two behind her, looking to her for guidance as to which direction they were walking. For her, his trailing behind became a sign of lost ability and increased dependence—because of his AD, he could not figure out or remember where they were going, so he must rely on her. That it could have been read as a rather astute modification—as he could no longer rely upon himself to navigate, he used her to do so—did not occur to her.<sup>7</sup> Others would talk of compensation, about a diagnosed person who adopted alternative strategies for living with Alzheimer's. Making lists to jog one's memory is a common example. Or when a person responding with a laugh or a general expression of enthusiasm rather than a more specific comment in a conversation when she's momentarily lost the thread. Or proceeding in a more circuitous order when following directions because it is more familiar. One husband described his wife "compensating" as she found she could no longer read:

I didn't realize that [she] had lost the ability to read. And the reason that she masked it was that, we were living in [an apartment]...run by a hotel, so dinner was from room service. We didn't cook. And she had the menu memorized. And I'd say, "What do you want for dinner?" And she'd say, "Oh, you know, I think I'm gonna have that hamburger." Or, if we'd go to a restaurant she hadn't been to before, she'd say, "What do you think looks good?" "The fish looks great!" "That sounds good to me." And it was months, literally months, before I realized she had literally lost the ability to read a menu because she compensated (0.5) so well.

---

<sup>7</sup> She had become his personal GPS, which points to the actual line, of course, as not one between independence and dependence, but between acceptable or normalized and unacceptable or pathologized dependencies.

In the context of Alzheimer's disease, the irony of seeing memorizing a menu as somehow less because it was compensation for an inability to read was lost. Compensation became a marker of loss rather than an indication of ingenuity. Those living with Alzheimer's are so steeped in the dominant discourse of AD that these moments can only be non-actions, futile against Alzheimer's in the longer trajectory of decline.

Across moments like these, Alzheimer's disease becomes a more prominent, explicit actor, not just in narratives but in social relations. Recall the couple who came to describe their relationship as a *menage a trois* with AD as the third partner. Given the individualizing processes that work to tie AD to a single person, however, the inclusion of AD in social relations is less an addition of a third than a redistribution of the diagnosed person's actions across two actors. One husband told me, in a conversation about how he viewed caregiving as part of his commitment of marriage, about how his wife once said to him, "Why don't you just divorce me and get rid of me?" I asked him whether he thought she was serious, given that she was not the only diagnosed person I heard suggesting that they be "gotten rid of" so as to remove burden from their spouse. He said he didn't think so, "That was the Alzheimer's talking. It never came up again." In that moment, Alzheimer's was a participant in their conversation, acting through his wife. By attributing her words to Alzheimer's, he deflected the possibility that his wife could be serious in her suggestion, avoiding the implications of that. More, though, he deflected her potential for action. Increasingly, the action of Alzheimer's disease obscures the possibility of the diagnosed person meaningfully acting.

## The Non-Action of Family Caregiving

Caregiving also is conceptualized by non-action. Despite what might have been a legitimate “commitment to winning support for caregivers” (Ballenger 2006: 118), activists’ rhetoric has left little room for caregiving as a possible means of intervening in the coming crisis of Alzheimer’s disease. Unable to cure, the work of caregiving has been articulated as, at best, an unproductive but necessary stop-gap and, at worst, the deleterious outcome of an Alzheimer’s unchecked by biomedicine.

Consider the words of Meryl Comer, noted family caregiver *cum* Alzheimer’s activist, who opened up the question-and-answer portion of the 2010 Congressional hearing, “Until there’s a cure: How to help Alzheimer’s patients and families now,” with these comments:<sup>8</sup>

We've had this conversation for 25 years, *with no action*, with the same issues. I would like you to fast-forward and create a sense of urgency in how we manage a pending epidemic, with a baby boom generation beginning to turn 65 January 1 of next year. ...So I applaud your efforts, Mr. Shook, around the quality of care, but *you are dealing with the consequences—not the cause*, often. ...[U]nless we marry the issue of research with care, and add the call for more basic research around the cause and finding some disease-modifying drug, we are in serious trouble. (2010, 101-103, emphasis added)

Rather than focused on current understandings of the causes of dementia or its potential cures, the hearing was convened to discuss innovative methods for providing care to persons and families living with dementia, from funding to training to the development of facilities and programming. Yet, in the first comment after the panel’s scheduled presentations, Comer switches to a discussion rooted in the logic of the coming cure, advocating a push for increased

---

<sup>8</sup> As Comer told the Committee: "I'm President of the Geoffrey Beene Foundation Alzheimer's Initiative, and I'm a member of Us Against Alzheimer's, I'm also on the Alzheimer's Association Board, but my comments to you are as a caregiver of 17 years, for both my husband and my mother."

“basic research around the cause and finding some disease-modifying drug.” In the process (applauding efforts aside), she discounts the conversation to address quality of care as inconsequential, as resulting in twenty-five years of “no action.” When Comer speaks of no action, she is not noting that the decades-long conversation has led to little improvement in care infrastructure, a charge she could readily level. Rather, her words, arguing that care can only “deal with the consequences,” devalue the work of care as little more than an ineffectual, downstream hand raised against the coming flood of Alzheimer’s patients.

While she says “no action,” Comer’s words resonate more strongly with a perception of caregiving as non-action. Families—Comer herself (Comer 2015)—are well aware of the daily work of caregiving. The activist and research communities are aware, as well, frequently pointing to the burden of caregiving on both individual and population levels, citing millions of “lost” labor hours, economic costs in the billions of dollars annually, and critically compromised health (e.g., Hurd et al. 2013). Family caregivers are *doing* things, and their work increasingly is recognized. Yet, the actions family caregivers take are still not recognized as meaningful. Speaking to those assembled for the ADC conference that May afternoon, Petersen evinced this understanding of non-action, rendering himself metaphorically immobile, “standing there,” unable to “do anything” other than “watch Jan fade” a little more each year. He says he is unable “to help,” despite detailing a great amount of work he had done. Jan herself is left with a “great sense of fighting back” that, in the end, might only have contributed to their denial of their shared fate at the hands of Alzheimer’s. While much is made of the amount of work caregivers do, the kind of work entailed within the caregiving relation—to attend to people’s needs, concerns, desires, and wishes as they live with the condition—is understood as “nothing to do.”

The pervasive sense of non-action shapes how family caregivers, outside of a public spotlight, understand their lives and the work of maintaining family, work which includes caregiving for those living with Alzheimer's. Craig Donnelly is a man who enjoys his folksy sayings, the form lending a common sense patina to his views on everything from the current government to life in the small Midwestern town where he has lived most of his years to the successes and failures of his beloved alma mater's football team. Our conversations—which often started over coffee at the dining room table in his now-too-large feeling house, moved through a meal with his wife Lisa at her long-term care facility, and ended a good while later at a local pub over a burger and a beer—were smattered with the shorthand sayings. His use of the sayings dovetails well with the wealth of self-help styled media for families living with Alzheimer disease, which frequently offer distilled advice for people diagnosed with AD and their family caregivers such as “Be in the moment,” or “You [the caregiver] have to be the one to change now.” Since Lisa was diagnosed with early-onset Alzheimer's disease in 2004, he has become familiar with many of them, and oftentimes Craig's sayings derive from the circulation of these materials through both popular media and more specific outlets like support groups, caregiver organizations, and dementia conferences.

Of Craig's many sayings, one in particular caught my attention every time he would use it: “Whatever I've done or haven't done, we'd still be in the same place.” Frequently, he would say it when discussing how he felt about where he and Lisa were in their journey. After she fell in their home, Lisa had moved to the memory unit of a nearby long-term care facility in 2008 because he “could no longer care for my Lisa in my house.” Since 2009, when she'd had pneumonia, she has been on hospice. When I first met her in early 2011, she was spending her

days in either her hospital-style bed or her wheelchair; she did not talk and rarely opened her eyes, but often she would smile when Craig kissed her cheek or while he talked. In addition to the care facility staff, he continued to employ two additional caregivers, who helped Lisa and visited with her during the day as they had since 2005 when he'd first hired them; talking about the decision to do so, he would say, "I felt that, when she could comprehend, she felt better when they were around. And," he continued, dropping in another of his favorite sayings, "when she felt better, I felt better." He visited her for dinner every day except Saturday; he and the afternoon caregiver would chat about Lisa's day, and then he would help Lisa eat, sometimes spending time with the other residents in the dining room, others just visiting with his wife in her room.

During our first interview, then, I was surprised when he said, talking about not feeling guilty about anything he'd done, "Guilt is the feeling I get when I could have done something different to affect the outcome. And no matter what I did or didn't do, it's not going to change the outcome for Lisa." I asked why he thought his actions would not have changed anything, he talked about the inevitability of the course of Alzheimer's disease. "Because of the disease itself. It's terminal." Later in the same conversation, he talked further about this trajectory: "You're the one who has to change; they're not going to. They've made a change, but they're not capable of going back. They're going the other way."

A year later, Lisa had suffered another bout of pneumonia that Craig was certain would be too much for her. He had called his sons back from their homes in California and Pennsylvania, and together the family, the caregivers, and the facility's staff prepared for her death. However, she stabilized after a few days; her swallowing had become more labored, but little else changed. Talking afterward, he said again, "I've reconciled my life with Lisa, and what

I have done or haven't done is not going to make any difference in the outcome. No matter what I did two years ago, five years ago, ten years ago, twenty years ago, we'd still be in the same place."

Within the logic, not only is the work of care that families do devalued, but families often feel guilt that they are not doing enough to find a cure. At a Memory Clinic support group meeting, Miriam, a fellow spouse and caregiver, was talking with Craig, who had been talking about feeling guilty because "You know, I should be doing something for her [Lisa]." Miriam insisted that, "You are doing a lot for your wife. Your wife is in a good, safe situation." Craig agreed, but his choice of words tellingly devalued that which he was able to do, "I can't do anything more for my wife than what I'm doing." He was not able to act beyond what he was already doing, the work of caregiving and family, which seemingly was not enough for him. Or Miriam, for as she then admitted she often found herself thinking, "'But I'm not coming up with a cure.' And I know it's not reasonable to think that I'm gonna figure out the cure. But still it's like—" she hissed in exhalation, shaking her head. "You still feel you should be able to do something," Craig replied. "Something," some action, cure.

The link between the work Craig had done as a husband and caregiver to, as he said, "provide and protect" his wife and the "same place" where he found both himself and Lisa was not inevitable, yet it was intensely overdetermined. The link was one of inefficacy, specifically the inefficacy of caregiving, of the work of families living with Alzheimer's. His actions had no effect on Lisa's condition, and Lisa could take no action of her own, she was "no longer capable" of making a change. Caregiving, in his description, became ineffectual when placed up against the inevitable, terminal progression of Alzheimer's disease.

## **The Extraordinary Nature of Caregiving**

Along with evaluating the actions of those diagnosed and their family members against the metric of cure, as families come to understand their work in the context caregiving, much of the activity, the labor of family maintenance is rendered invisible as it is considered “ordinary.” Family caregivers, in particular, come to understand their own labor in terms of caregiving alone. In support groups, interviews, and informal conversations, family members continually evaluated themselves in terms of the labor generally recognized as caregiving, especially that which supported a diagnosed person’s activities of daily living (ADLs).

Bridget Reynolds, for example, was married to Alex, who had been diagnosed with early-onset Alzheimer’s. In October 2011, I spent part of a visit talking with Bridget alone, while Alex played with their overweight golden retriever Albie in the backyard. They had recently gone through some larger changes, and Bridget spent much of the time telling me about those. She talked about still working full-time as a social worker and assistant principal in a middle school, and how Alex spent most of his days at home, riding his indoor bike, walking Albie, and doing errands around the house. Yet, she was noticing changes, she said, “seeing some things go on in terms of the loss of memory.” She told about a time that Alex was doing laundry and a hose on the washing machine came loose, spraying water across the room. Alex could not figure out how to stop the water or reattach the hose. He grew increasingly frustrated, shouting at the machine with angry impotence. Which made it all the harder when she came downstairs, shut off the water, and fixed the hose without trouble.

She also talked about hiring a home health worker. Over the preceding summer, Alex had had to quit driving.<sup>9</sup> After that, Bridget arranged to have a woman, Maria, come to their house a few hours every afternoon; she would spend time with Alex, drive him somewhere if need be, cook dinner for the two of them, and help with other tasks around the house. As Bridget said, she was trying to acclimate him to having someone in the house “for when he needs more care.” Alex initially disliked the idea of having someone helping out at home, saying that he didn’t need it, that he felt like he was doing okay. She told him that it was mostly for her, that she wanted to lose some weight, to take care of herself, and that any exercising would only fit in the schedule after work. She said that she needed help keeping up with everything that needed to be done. She said he found this acceptable, and by the time we had a chance to sit down and talk, Alex talked about how good it was to have Maria around.

Given this change in the household dynamic, I asked Bridget about how she was now thinking of her and Alex’s relationship, specifically if she thought of herself as a caregiver. “Oh, yeah,” she responded immediately, “Yeah.” Then a pause: “You know if I were comparing myself right now to Maria, it’s Maria. More so.” I asked her why. “Because she’s here specifically for the purpose of doing caregiving kind of stuff. I still think of myself as his wife. You know? So, if you’re gonna have a line of demarcation there.” “Is there one?” She thought for

---

<sup>9</sup> Driving often is a challenging and sensitive issue for many families living with dementia, one that seems particularly charged for men among the generations currently dealing with dementia. However, Bridget told me that she discussed the danger of an accident as a person diagnosed with dementia with Alex: that it would be horrible were he to hurt anyone, himself or others; that the diagnosis would automatically make him appear culpable, no matter the situation; and that that could be devastating to them financially. He agreed that it had become too dangerous and decided to stop.

a moment: “I don't know. Probably not. When you think about it, now that you're asking. Probably not.”

A year later, in November 2012, I again asked Bridget to describe their relationship. Alex could no longer walk Albie on his own because he had gotten lost a few times; he had had to switch to a recumbent indoor bike after he fell trying to mount his traditional racing bike; his gait was becoming increasingly unsteady, a change that had Bridget thinking about modifications that could be made to the house so Alex could live on the main floor. After a long pause, she said, “I feel like more of a caregiver. Because of the day-to-day things that need to happen for him. Basic care, you know, kinda stuff. I have to help him with the shower, make sure he's really washing his hair and getting himself cleaned up and all that stuff. I have to help him with his clothing, I have to help him remember things. You know, there's just—I'm more on him as a caregiver than I was before.”

Definitions of family caregiving circle around a few consistent themes: engagement in activities to support family members' selves and bodies; assistance provided to a person who cannot complete these activities for themselves; and a medical complication inhibiting their ability to do so. Given these, many of the activities of family maintenance could be considered caregiving. Yet, as caregiving scholars Richard Schultz and Lisa Martire have written, “[T]here is general consensus that [caregiving] involves the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships” (2004: 240).

Before the more complete assistance with activities of daily living that is well-recognized as caregiving, family members frequently discussed the boundaries of caregiving in terms of the

gendered division of familial labor.<sup>10</sup> Often when wives complained about the labor of caregiving, it was about the work that their husbands used to do, frequently fixing or maintaining things around the house. In an early interview when I asked about feeling like a caregiver, one woman told me about taking over the finances, a task that been husband's, and many of the activities in the yard, from the upkeep of their elaborate garden to figuring out snow removal in the winter. At another point, she talked about cooking meals. Chili was her husband's specialty, but other than that, she said, he was never the cook. The labor of cooking meals was not something she noted as unusual. In contrast, male caregivers would talk about learning to cook and taking on housework such as straightening and dusting as part of their education as caregivers, activities that became theirs as their spouses could no longer keep up with them. As much as the medicalized nature of caregiving, the gendered boundary of the extraordinary sorts activities and actors into caregiving or "simply" family maintenance.

This line of the extraordinary was the one Bridget ultimately used as her marker. The line between extraordinary and ordinary characterized the extent both of her labor and of Alex's debility. In this way, the line was one that marked dependencies, some acceptably invisible as the division of labor across gendered households and others unacceptably, "extraordinarily" necessary-but-burdensome, visible acts of caregiving. Bridget felt like a caregiver the more her actions fell outside the bounds of that latter, invisible labor, the more she had to help Alex with what she saw as "basic care"—the showering, dressing, and eating of ADLs. Yet, in doing so, she relegated her work to maintain her and Alex's relationship: the "bucket list" trips they dreamed

---

<sup>10</sup> See, e.g., Dalley (1988), Hochschild and Machung (2012), Hooeyman and Gonyea (1995) and.

up together that Bridget made actualities; the weekly Friday night date nights she continued to organize as a tradition of theirs, eating dinner at their favorite local Italian restaurant followed by watching reruns of the Three Stooges; the small, everyday moments of conversation or laughing or holding hands. In that paradigm, all these became something else, something that—in evaluations of caregiving—was lesser.

### **One Family's Day: The Erasure of Family-Making**

In this final section, I want to consider what daily life in the context of family caregiving and Alzheimer's disease looks like, how it is rendered through the lens of non-action. To do so, I turn to the Smiths, Kevin, who had been diagnosed with early-onset AD, and his wife Susan.

A few months after Petersen's presentation at the ADC conference, Kevin and I were spending time together at the Smith's house late one autumn afternoon, waiting for his wife Susan to return home from the local elementary school where she worked as a fifth grade teacher. That morning, I had picked Kevin up and driven him to a biweekly day program for people diagnosed with dementia, a diagnosis he was given in late 2009. Group members were usually dropped off around 9:00 AM, and the program would last until around 3:00 in the afternoon. The day program was structured around a series of field trip excursions or activities, a mix of educational and interactive. Most often, there would be one activity in the morning, then lunch, followed by an afternoon activity. That morning, the group had a music program in the morning and a tour of the state's Department of Transportation's communications center. Other trips included nature centers or parks, a restaurant where they made their own pizzas, Fermilab, several museums.

Later, on the ride home, Kevin talked a bit about the program. He acknowledged that he didn't always like the activities, but that it gave him something to do during the day and that was nice.<sup>11</sup> They filled time. Much of Kevin's days, like those of many diagnosed persons I came to know, were characterized by a lack of structure and activity. Since he stopped working as a technical manager for broadcasts of major sporting events shortly before his diagnosis, he often walked to town, which was nearby his and Susan's home, or around his neighborhood with the Smith's dog; he would occasionally take the train into a nearby suburb for a support group meeting or, as with me, get a ride to the day program every couple weeks; and he spent a lot of time around the house, again with their dog or playing his guitar.

As we returned to their home, Kevin got us both a glass of water, and we settled in the living room to continue the conversation. He talked about feeling lucky that he could communicate, that we could have the conversation we were having or that he could talk to his wife and two sons. Joe, by contrast, or Jonathon, he said, had so much more trouble expressing themselves, getting their thoughts out. He told me about the past week, which he'd spent with his

---

<sup>11</sup> As many families, both those diagnosed and their spouses, noted, the program was geared toward those with the more typical late-onset Alzheimer's disease, people in their 70s and 80s. Yet, several of Kevin and Susan's friends, also living with early-onset, attended the program, comprising at least half the members on any given outing. This day, we had spent the morning listening to a music program of mid-century pop standards sung by a middle-aged woman with a band provided by iPad. "Big Spender", "Que Sera Sera", "Moon River": they were the kinds of songs that one might assume would be popular with older persons, but were unfortunately discordant with the largely younger group assembled that day, whose tastes ran more toward the rock-n-roll of the 1960s and 70s. During the afternoon, we toured the state's Department of Transportation's communications center, which monitors traffic flowing through the a large metropolitan area and across the northeastern portion of the state. The group seemed to find this more interesting than the morning music, especially as the director of the center told us about the huge volume of calls they received daily, the constant contact with emergency services, and the daily reversal of the express lanes that ran up the center of one of the city's busiest stretches of expressway.

father-in-law, helping with some labor at the older man's cottage in northern Wisconsin. Both he and his father-in-law had been frustrated working together, and the emotional residue stuck with Kevin. Later, Susan would tell me that her father had not understood what it was like to work on projects with Kevin anymore, given his cognitive changes. She talked about how it was to work on a task together, that he required increasingly detailed instruction, guidance, and reiteration. She also told me how tired he would get, a weariness that was as much mental and emotional as it was physical, one that often made him short-tempered after a day of work.

Kevin and I chatted about other things, too—the new Steve Jobs biography caught his eye, at one point, and he talked about what a bully he thought Jobs was, pushing people around to get what he wanted. From that, he moved to talking about the memoir of a man with Alzheimer's, who had been born “near Chicago, but then moved somewhere south.” He thought the man's perspective was on point, recommended the book to me as someone who was interested in the experience but could not remember the author's name.

Often when I visited the Smiths, I would spend the afternoon with Kevin as I did that day. We would talk about what he has been doing, played with his dog in their backyard, and sometimes a beer. I listened to him play guitar or to one of his favorite CDs. The rhythm of the time was easy, for the most part. When Susan came through the door in the early evening, that all would change.

That evening, Susan came in just after 5:00 PM in a whirlwind of energy. She dropped the mail on the counter, along with a container of WD-40 to fix a squeaky hinge, which she had bought on the way home. Without taking off her coat, she started a pot of coffee, dropping a filter and the needed number of scoops of ground beans into the top, whipping the pot over to the sink

to fill it with water, which she then poured in the back. As she switched it on and the hot plate started to sizzle the water that had splashed over the pot's side onto the bottom, she said, "That's the slowest coffee pot in the world!", and headed upstairs. A moment later, she returned with a teeming laundry basket, which she carried downstairs to switch out with the load she'd started that morning. Back to the kitchen, she checked the coffee maker's progress, poured herself what little had collected, and talked with Kevin and I about our days. Kevin asked her about her time at "the prison," and she moaned that they must be trying to get everyone to quit. We told her about how we'd spent the day, everyone laughing about the music programming. It came up that Kevin and I had been talking about an Alzheimer's memoir, and Susan asked Kevin if it was Richard Taylor's.<sup>12</sup> She said she thought it might be downstairs, "in a box labeled 'Alzheimer's stuff'", that they initially had done a lot of reading on Alzheimer's disease but as they lived with it, "she lost interest." Finishing the few swallows, she set her mug on the counter and announced she had to head to the bank. While she was gone, Kevin and I headed into their basement to look for a copy of Taylor's book. We wandered about the storage areas of the downstairs, looking through boxes, on shelves, getting lost among his guitar collection. Kevin showed me a framed collage of press passes, photographs, and memorabilia from his days as a technical manager, sharing a story or joke about each piece. Eventually, as she returned home, we made our way

---

<sup>12</sup> Richard Taylor was a psychology professor who, when he was 61, was diagnosed with dementia, "probably of the Alzheimer's type" (2007: 7)—as he always highlighted the uncertainty of diagnosis. He helped to found Dementia Alliance International, a "a global group, of, by and for people with dementia, advocating for the voice and needs of people with dementia" (<http://www.dementiaallianceinternational.org/about-dai/mission/>, accessed April 11, 2016). He also wrote and lectured extensively about living with the diagnosis, advocating for the continued recognition of the personhood of those diagnosed.

back upstairs. She also had stopped at the grocery store to pick up some beer, and put that in the refrigerator, even as she started another load of laundry and began working on dinner.

Once dinner was cooking, the pace of the evening slowed a bit. We all talked as Susan emptied the dishwasher. I tried to help, occasionally stirring pasta or misplacing a mug in the cabinets. Kevin fed the dog and then grabbed his guitar, providing improvised accompaniment to our talk. Susan showed me engagement photographs on the computer that one of her sons and his fiancé had recently had taken. Conversation during dinner wove not just around life with Alzheimer's, but through discussions of her work, Kevin's recent troubles with a blood clot in his leg, their sons' goings-on, and other day-to-day happenings that we hadn't been able to catch up on in a while. After, dinner was cleared and dishes in the dishwasher, laundry was dried, and a bit more conversation was had. As the evening wound down, Susan went upstairs to shower and get some sleep before another early, school-day morning, while Kevin shared some of his favorite music with me on their CD player for a while before turning in ourselves.

Across this day, one little different from any other for the Smiths, both Kevin and Susan did an enormous amount of work. Yet, as the couple is seen through the lens of Alzheimer's disease and family caregiving, little of this work is meaningful. Their work might be viewed as contributing to Kevin's comfort and quality of life, but in a paradigm where Alzheimer's disease and that which cures it are seen as the only viable actors, it doesn't count for much.

Kevin was only capable of non-action. He expressed being acutely aware of this inability to act meaningfully. He often talked of work, of his time there, the hectic nature of the always-traveling schedule, and his and his friends' continual on-the-job antics. The stories were a stark contrast to his current life. A few months later in a support group meeting, Kevin would talk

about feeling “invisible” in his own home, about “moving away from my family. ...I can walk through the room, and nobody’s there. I try to keep myself busy as much as I can, but that just gets old, too” The increasing invisibility of which he speaks is related to his inability to act—as he walks through the room, no one notices because he is unable to make an impression.

The contrast of his and Susan’s lives in their home accentuated his sense of non-action. He filled time with a version of what notably often is referred to, both colloquially and professionally, as “adult day care.” He was not able to transport himself there or home. He could not run errands. He was unable to help with shopping, laundry, or dinner. He sat, playing guitar or partaking in the conversation, while Susan hurried around, making the evening happen. In contrast to the expansiveness of his time, hers always felt crunched, overrun. The rhythms of their days, movements through the house, and abilities to act were dramatically different, and both were affected by it. Kevin would tell me that he knew that Susan “has to do everything now,” and how much “it sucks.” He talked about wanting to be able to do more, about being disgusted that he could not, referring to himself derogatorily as “the ‘tard,” a slur that underscored the extent to which their different routines in the house—a disparity brought about by his increasing inability to act on the world—undercut his sense of self.

Susan, too, was a non-actor in the evening. Was Susan caregiving during the evening described above? Were her meal preparation, her errand running, her laundry washing acts of caregiving? Susan was not one to downplay the household labor she did; often, she would talk about how busy she was between her work as a teacher, a parent, a spouse. And much of what she did that evening could be considered caregiving. Her work that evening revolved around the sustenance of the household and those in it. Kevin was no longer driving, so running errands was

an activity he could not complete himself; while he did get us water, he spent a long while looking for the glasses, so he likely would have required help with cooking dinner; he might have been able to do laundry. The reason for Kevin's difficulties completing these tasks was his cognitive changes, attributed to Alzheimer's disease.

Yet, one thing that was striking about the work that Susan did throughout that evening is how normal it was: she runs errands, makes coffee, cooks dinner, does laundry, empties and refills the dishwasher. The evening likely resembled the evenings of many families across the US who were not living with Alzheimer's disease. In many ways, it likely resembled many evenings the Smiths themselves had before Kevin was diagnosed. Even though Susan and Kevin's division of household labor was more equitable than many, it was still divided, and many of the tasks that evening fell on Susan's side of the divide. Her work was in support of those invisible, acceptable dependencies. At other moments of the day, she would have helped him choose clothing for the day or clean up where he had missed the toilet while urinating. Those interactions might have been considered more outside the norm of the Smiths' relationship. Months and years later, she would have to help more completely, feeding Kevin, helping him bathe, go to the bathroom, but not that evening. To Susan's mind, despite how much work she did, there was little "extraordinary" about it, so it fell outside the bounds of caregiving and became non-action.

When both Kevin and Susan understood their work as non-action, they missed the vital work of family-making that occurred that evening. Friendships were solidified as Kevin and I chatted about sports, funny stories from working or his childhood, his guitar collection and playing guitar, and my life. As we all talked about their son and his fiancé's time working in Kenya and my own wife's research in South Africa, cooking and food, and Susan's always-

fraught relationship with her school. As we focused more closely on their lives with Alzheimer's, how they had been affected, what their interactions with clinicians had been like. The food she cooked was part of that work, as was the guitar accompaniment he provided. The errands she constantly moved between. Playing with their dog. Listening to music on their stereo. Relations were woven and re-woven, strengthened and changed, across that evening. Critical domestication work—work that maintained families and reworked Alzheimer's disease—was accomplished. Yet, that work, unfortunately, went mostly unnoticed as “doing nothing.”

## **Conclusion**

Once a person is understood as having Alzheimer's disease, both that person and her family members become increasingly non-acting subjects. Despite the work they do, the narrative of Alzheimer's disease and family caregiving within the logic of the coming cure portray them as unable to act meaningfully. The actions of diagnosed persons are interpreted as symptoms of their increasing debility, actions of Alzheimer's itself, or pale attempts to compensate. Family member's actions come to be seen either as ordinary family labor or, once understood as caregiving, ineffectual acts unable to meaningfully contribute to finding a cure. These portrayals ripple across the spaces and scales of public presentations, Congressional hearings, activist materials, memory clinics, support groups meetings, and people's homes and daily lives. Families come to understand themselves in terms of non-action, articulating and enacting themselves as non-actors, both explicitly and implicitly. As they do so, the work of family-making becomes increasingly more difficult to recognize and appreciate.

In the following chapter, I further explore the effects of this logic of a coming cure and the trajectories of Alzheimer's disease it imposes upon families and their ability to navigate, make sense of, and hope for a future.

## Chapter Four--Five More Years: The Temporality of Hope

*“I had a dream the other night when I was writing up my notes about Jacob’s death, Shmuel. A man of great wisdom, a doctor, told me I had a fatal disease. ‘You cannot remedy it,’ he said. ‘There is nothing I can do for you except to give you this advice: Do your work as well as you can. Love those around you. Know what you are doing. Go home and live fully. The fatal disease is life.’”*

*--Myerhoff, Number Our Days (1978: 231)*

### October 2012

Nineteen of us crowded into the church’s Youth Room for the breakout meeting of caregivers who felt their family members were in AD’s latter stages. Late morning October sun, unusually warm, shone through the high-set windows, dappling the long-ago broken down couches and minimally padded chairs that composed our misshapen circle. Craig was there when I walked in, and he joked about being in his usual seat; no longer attending with his wife, he was usually among the first few, along with Tom, dressed perennially in his cardigan and buttoned down shirt. After helping their spouses to where they were going, other joined us, some with cups of mediocre coffee, others with a remaining bite of frosted brownie or cream-cheesed bagel. Helen came trailing in toward the end, pushing her walker in front of her—the elevator always took forever. She found a place to park her walker, turning it around and sitting on the built-in plastic seat.

That morning, as moderator, I began by welcoming everyone and asked if anyone had something they would like to discuss. As the last people settled around the circle, everyone waited to see who would start, and after a moment, Helen broke the brief silence:

Well, I was down to the veteran’s home yesterday, for Jerry’s care conference. And the feedback I got was, “Well, he’s doing quite well.” I mean, all of a sudden, he’s going to the exercise room— first of all, I should say that I stopped his Alzheimer’s

meds. So now he's going to the exercise room, he's riding the bike, which he never did before, and he seems to be much more...um, with the program, so to speak. And I have to tell you [laughs quietly] I was a little disappointed when I heard that. Because I was sort of on this trajectory where he was gonna get worse? And now, all of a sudden, it seems like it's taken this step back and he's doing quite well. And I like, "[sigh]..." But that's how I felt when they were telling me this. You know? It's sorta like how, how much longer is this gonna be? You know?

Around the circle, some people's visual contact cuing their roles as responsive listeners, while others' unfocused gazes were turned both toward the center of our group and inward. Either way, people nodded slowly, a nonverbal acknowledgment of agreement or, at least, understanding. Helen went on to say that she asked a nurse at the VA Hospital what the longest was that someone had been on the unit and was told that there were some men who'd been there since it opened, about eight years. Craig spoke about his wife, who "went to the neurologist first time in 2002" and had been on hospice going on three years since 2009, "usually about a six month deal, k? ...And what I'm leaning to," he continued, reciting a mantra common among people living with dementia, "If you know one Alzheimer's patient, you know one. There is no two—our paths are not the same. K? And you're very fortunate that you're having...he's doing well. But all of a sudden, like Lisa goes this way, and then—" his flattened hand traveling along horizontally through the air before cutting to slope quickly down, a gesture that articulated the plateaus and rapid declines that many family members described over my fieldwork. Tom cut in, "But I identify a lot with what Helen's saying. Holly kinda went through the same thing. They took her off Namenda, and some of that stuff, and she got better. It surprised me—like everything—and...that felt good in a lotta ways, but how long's this gonna go? ...How long, oh my stars, is this gonna keep going forever?"

The question that animates this chapter is, How does a person get to the point where Helen and the others were? When a spouse's improvement, even if temporary, is no longer welcome?

Helen asks: "How much longer is this gonna be?" Tom asks: "Is this gonna keep going forever?"

These questions are temporal ones. They are questions of duration: How long will the present be and what are the possibilities for the future it will eventually bleed into? Intertwined with it are another series of questions, ones that continued to dig at me in the months of research and writing that followed that morning: How do families living with Alzheimer's understand their present? And how do they envision the present in relation to the future? How do families feel the possibilities for their futures are shaped? Within what constraints do they learn to evaluate, anticipate, expect? How do these possibilities align with the futures they had, to that point, been planning as families? How do families living with Alzheimer disease come to figure their own futures?

In the previous chapter, I traced how families come to see themselves as non-active agents in the world. They are people capable only of non-action, an action completed, but to no effect that they feel is recognized. People diagnosed with Alzheimer disease are rendered non-actors as clinicians, family members, and others increasingly attribute their actions to the disease. Under the shadow of an always forthcoming cure, family caregivers begin to feel their work has little value or effect, either not the extraordinary labor of caregiving or, even when it is, not enough to alter the course of Alzheimer's. In both instances, there is a sense of certainty about the future: people diagnosed with AD will continue to "lose themselves" to the effects of that

condition as it progresses inevitably, while family caregivers can do the work of care now, but that works value is erased by the promissory cure of the future. This chapter shifts from a focus on action and agency to foreground that underlying futurity. Through it, I articulate the ways that a construction of a kind of hope on one scale—in this case, a national scale of research and activism—can attenuate a different hope on another, smaller scale—here, that of families.

### **Families Living in Prognosis**

From the moment of diagnosis, if not accompanying earlier suspicions, families living with Alzheimer's begin to refigure their futures. Families are dynamic, continually engaged in projects of social reproduction across both generations and individual members' life courses. Family members' senses of time are, in part, structured by their involvement in or connection to these projects (e.g., Haraven 1977; Hagestad 1986; Lamb 2000; Neugarten 1979). They move through their life courses together, engaging (or not) in transitions, including birth, marriage, moving, divorce, retirement, death. As they do so, they plan, imagining the possibilities for the future, building hopes and expectations. While plans shift and futures surprise, hopes and expectations help to bound the range of changes, to temper their effects.

As families learn to live with Alzheimer's disease, their life courses are disrupted, and they are drawn into a different temporal regime (e.g., Becker 1997; Charmaz 1991; Kleinman 1988). In her writings about cancer, S. Lochlann Jain describes this new temporal regime as "living in prognosis" (2007; 2013, especially chapter 1).<sup>1</sup> Prognosis alters one's relationship to

---

<sup>1</sup> Similar to Hagestad's "out of time" and "threaten[ing] the very foundations of time structuring by removing you from life's comforting rhythms" (Hagestad 1996: 205)

time. “Living in prognosis,” as she writes, “severs the idea of a timeline and all the usual ways we orient ourselves in time: age, generation, and stage in the assumed lifespan” (2013: 29).<sup>2</sup> In the context of cancer, as Jain writes of it, the temporal timbre of prognosis is uncertainty; a person’s new relationship to time is articulated through the uncertainty of remission: Is this round of treatment a cure? Or simply palliative (2007, 78)? The uncertainty is attributable to the abstracting work of statistics, which renders a person’s cancer simultaneously a distributed, population-level risk of varying level and an embodied, individualized risk of a coin toss.<sup>3</sup> Prognosis seems to offer a glimpse into the future, but frequently just ends up clouding the mirror. Despite appearances of the universalized certainty of “scientific fact,” cancer prognoses leave one feeling deeply uncertain and unmoored in the present.<sup>4</sup>

As families describe it, the prognostic timbre of Alzheimer’s disease is one of certainty. The horizon of death crystallizes as the clinician tells the diagnosed person and her family that there is no cure, that treatments exist which can help the symptoms but there is nothing to reverse

---

<sup>2</sup> Particularly relevant to those living with early-onset AD, she goes on to write, “If you are going to die at forty, shouldn’t you be able to get the senior discount at the movies when you’re thirty-five? Does the senior’s discount reward a long life, or proximity to death?”

<sup>3</sup> Prognosis is both “stunningly specific (one has x percent chance of being alive in five years) and bloodlessly vague (you, yourself, will either be alive or dead)” (ibid).

<sup>4</sup> As Jain writes of it, “One is moved into an abstraction that *seems* explanatory through its gesture toward universality, yet one will only ever live or die. Either way, one’s future will only be absorbed into the truth of prognosis, a truth that recursively projects a future as it acts as a container for a present.” She continues: “[T]he treatments and the prognoses for many types of cancer remain remarkably inaccurate and even rote. Consider the fact, for example, that for breast cancer (which some physicians consider an umbrella term for perhaps two hundred diseases), chemotherapy increases survival rates by a mere 3 to 5 percent, and little is known about whom it will help. Of the seventy thousand women each year who undergo the treatment, five thousand may increase their survival time.” (79-80).

the course of Alzheimer's.<sup>5</sup> While orienting to a now-tangible horizon of death, those diagnosed and their families also must reckon with AD's temporality of decline. While, as Barbara Myerhoff's dream imparts in this chapter's opening epigraph, life itself is a "fatal disease," reckoning with one's own death is not perceived as part of the standard life course for many Americans in the middle years. Despite the potential appearance of previously unfamiliar aches, loss of strength, decreased flexibility or mobility, the normative expectation of "midlife" in the US is as a period of one's life during which one's body is functioning well and will continue to do so for years to come.<sup>6</sup> Alzheimer's disease overturns these expectations, forcing a person and her family to imagine new futures, searching for new hopes.

With little medical treatment available, clinical trials offer access to the promise of speculative biomedicine, and in the midst of what is felt as a bleak prognosis, they act as a source of hope.<sup>7</sup> They are an exemplary point of contact between the biomedical community and families, drawing the two together in a "biomedical embrace" that fuels hope in the promise of

---

<sup>5</sup> One family with whom I worked talked about was asked during the diagnostic appointment if they wanted to donate the diagnosed person's brain once he passed. "Seriously," the wife told me, "I mean, you're fifty-two years old, and you've never heard of this disease, and you get diagnosed with it, *and* they ask for your brain in the same breath?" While obviously an extreme—and extremely poorly handled—situation, it illustrates the immediate reorientation to the horizon of death.

<sup>6</sup> Sarah Lamb has proposed the concept of "permanent personhood" to describe this phenomenon, which, as she writes, is "a vision of the ideal person as not really aging at all in late life, but rather maintaining the self of one's earlier years, while avoiding or denying processes of decline, mortality and human transience" (2014: 45)

<sup>7</sup> Largely through the efforts of HIV/AIDS activists in the late 1980s and early 1990s, who fought for access to pharmaceutical treatments before FDA approval and ultimately changed the process of bringing treatments to market, clinical trials came to be seen as "simultaneously sites of scientific research and medical care" (Epstein 1995: 410).

technoscientific advancement (DelVecchio Good 2001).<sup>8</sup> Clinical research, both the advocacy rhetoric that surrounds it and the structure of the research enterprise itself, brings the promised future of a cure for Alzheimer disease closer, makes it tangible to families. Advocates deploy a language of imminence, wherein success is always just around the next corner. During my fieldwork, family members spent a great deal of time discussing them, in support groups, in medical appointments, and among friends who were living with AD. Several families were involved in clinical trials at different points, and those who weren't were, without exception, still involved in the conversations around them, with many trying to access trials.<sup>9</sup>

### **January 2008: Families' Hope for Clinical Research**

Four-and-a-half years before Craig, Tom, and the others found themselves listening to Helen's confession, a not dissimilar group of family caregivers were in the midst of a meeting in the basement of the same church, in a room down the hall. Tom was there, likely wearing his cardigan, four-and-a-half years earlier in he and Holly's experience with Alzheimer's. That January morning, the group spent much of their time discussing clinical trials—what trials were available, what the tested treatments were supposed to do, whose spouse had taken part in one

---

<sup>8</sup> “The concept of “embrace” conjured the affective responses of many clinicians and their patients when using new biotechnologies, high-technology experimental treatments, and even salvage therapies. . . .the enthusiasm that sparks the medical imagination also drives the political economy of hope, and our society's investment in medical adventures and misadventures.” (DelVecchio Good 2001:399)

<sup>9</sup> As will become clear in this chapter, a shift has occurred in the landscape of clinical research into dementia and its potential treatments away from the search for a cure and toward the search for measures that will prevent people from developing dementia. However, during the time of my fieldwork clinical trials still offered—at least for a time—the families with whom I worked the possibility to participate in a medical intervention that, for a time, they felt *might* work for people currently living with dementia.

and who would like to have their spouse do so, what the trials meant for families living with dementia.

The discussion opened with a back-and-forth about a clinical trial for a treatment, bapineuzumab, a passive immunotherapy approach intended to clear excess amyloid plaque.<sup>10</sup> A newer member, Eddie, piped up: “That Elan study, ...a friend of mine, he’s a stock guy, and...they’re talking about it, you know, if this thing does what it’s supposed to do, it’s gonna be huge, which I’m sure it will be.” He then asked what the treatment would do if it worked. Norma, a long-time participant whose husband was currently in the trial answered, “They’re not quite sure. But they’re hoping, possibly, it will remove plaques.” And others quickly jumped into the conversation: “Really?” “*Remove* plaques?” “Remove plaques and then maybe—” she continued, and was cut off by Marcia, a third member, whose husband was in another clinical

---

<sup>10</sup> Clinical trials for the treatment were discontinued in 2012, after no significant treatment effects were demonstrated. Margaret Lock writes of bapineuzumab and the trial: “[O]n July 23, less than a week later, an article appeared in the *New York Times* under the heading “Alzheimer’s Drug Fails Its First Big Clinical Trial.” Reporter Andrew Pollack notes that this deals “a blow to the eld, to a theory about the cause of the disease, and to the three companies behind the drug.” One of the companies is Pfizer, and they reported that the phase 3 trial of their drug, bapineuzumab—produced together with Johnson & Johnson, with further financial input from Elan—improved neither cognition nor daily functioning of the patients to whom it was given, as compared with a placebo. Readers were informed that “most doctors and Wall Street analysts had been expecting the drug not to succeed,” because the phase 2 trial had not been statistically significant. At the Vancouver meeting there had been no sign that this failure could be imminent, and the leaders in the eld must have been decidedly worried as they gave their upbeat messages. It is significant that in this trial the subjects, 1,100 Americans with mild to moderate AD, were all APOEε4 carriers, but the phase 2 part of the trial had indicated that the drug had a better chance of working with individuals without that genotype. In early August, following further disappointing results, in which noncarriers of the APOEε4 gene were the trial subjects, Pfizer and Janssen announced that they were completely halting development of bapineuzumab for mild to moderate Alzheimer’s disease. It is still possible that this drug will be made use of in trials designed to assess its worth in the prevention of AD” (2013: 215-6).

trial for the nerve growth factor Ceregene: “And then prevent it, if you start early enough?”

Norma responded, “Prevent it from moving forward. Maybe even reverse it.”

Hope was palpable in their exchange, and it continued to be evident throughout much of the discussion that day. Later in the conversation, Marcia would talk about her husband John’s improvement during the course of his clinical trial: “[I]t, like he—really, his decline probably slowed down. And the statistics somewhat show that. And he, there was a particular part of his brain on his PET scan...that showed a little improvement.” Tom talked of the potential of clinical trials that morning in 2008, as well, saying that he “would just jump at the chance” to be in a study, that “we would try anything. Because I, because this, it’s just gonna get worse. It’s just not gonna get better. So anything that could possibly, uh, make it better, I’d be ready to try.”

The group’s hope was seemingly flush with the possibility of improvement that Helen laments. Thirty-eight words carried the group from a vague promise of “not quite sure” to clinical research’s potential of “maybe even reversing” Alzheimer disease. Marcia talked about witnessing improvement, evidenced she felt both in a deceleration of John’s decline and in one of the trial’s PET scans. Tom told those assembled that he would “jump at the chance” to help his wife Holly. “Yeah, I’d be willing to take some huge risks there,” he said, “just to, just to...somehow, if she could get some quality of life back, that she knows kind of what’s going on. Cause she just doesn’t.” His enthusiasm appears incongruous when placed up against his 2012 comment that, despite feeling good about the changes in Holly once her medication was stopped, he still wondered how long things were going to continue.

In many ways, however, both groups were working around the edges of a single discussion, one concerned with futures: how they are envisioned, what the range of possibilities

are, and how one orients toward them. Orientations to the future are anticipatory, balancing the uncertainties and risks of multiple possible outcomes (Adams, Murphy, and Clarke 2009). In her work within a cancer ward in Botswana, Julie Livingston discusses how clinicians, patients, and families within the ward often have different visions of the future and that part of the work within the clinic is “managing different horizons of hope, which over time merge into a gradual if often unsatisfactory alignment through the processes of treatment” (2012: 55). She describes how families often arrive hoping to feel better, well enough to engage in a meaningful future, while for clinicians, “efficacy means shrinking a tumor, and preventing or halting the process of metastatic spread” (81). In her discussion, as cancer is consolidated as a biomedical object, available for treatment, these horizons can converge, even if imperfectly. In both support group discussions, family members also are engaged in such projects of managing horizons of hope. The distinction between the two groups’ conversations might be envisioned as different—and differently satisfying—alignments of these horizons and the implications for the future. The question becomes: Why are the two groups’ perceived futures so different? In the remainder of the chapter, I argue that it has to do, in large part, with the potential for convergence, what it means when the horizons at play begin to merge. Yet, anticipation is not always hopeful; it also can be despairing, depending on the future one envisions and the potential to realize or avoid it. Both the 2008 and the 2012 groups were struggling to reconcile a range of futures, anticipating possible outcomes for themselves and their spouses.

### **The Future(s) of the Coming Cure**

Families' orientations to their futures are structured by the logic of the coming cure, which affectively organizes the temporalities of Alzheimer's disease. The very idea that a cure is coming is temporal: The cure exists, lying in a future toward which the present steadily moves; at some point, they will converge. And in the prominent messaging of advocates, clinical research is the tool to effect that convergence. The research community is on the cusp of a breakthrough that will carry everyone into the future with a cure: "For the first time in history, there is real hope in emerging science that we can overcome Alzheimer's disease and that the day is near when Alzheimer's does **not** need to be a death sentence" (Alzheimer's Association 2011: 14). The content of this future—the eradication of Alzheimer's—is clear, and the affective orientation toward that future, toward research's power to actualize it, is one of hope.<sup>11</sup>

As advocates write of it, hope seems the product of scientific advancement and a collective faith in that progress. The rhetoric points to a history of successes. A 2009 report by the Alzheimer's Study Group (ASG), which became the basis for the subsequent development of the 2011 National Alzheimer's Project Act (NAPA), compares undertaking this "ambitious mission" to other "Great American Projects": the construction of the transcontinental railroad, the building of the Panama Canal, the Manhattan Project, the Apollo moon landing, and the Human Genome Project. Each undertaking is listed in a graph, along with its date of initiation, success date, and the duration of the project. The "Alzheimer's Solutions Project" leaves the last two—success date and project duration—blank. Just above, the report's authors write: "All of these projects were similarly daunting when first proposed. Yet, in all cases, America proved

---

<sup>11</sup> As the Alzheimer's Association's materials inform their audience: "Our vision is a world without Alzheimer's" (website). Their annual fundraising walk is marketed as the "Walk to End Alzheimer's". [others - Shenk's Forgetting]

itself capable of accomplishing great missions when those efforts were backed by a sustained commitment, entrepreneurial spirit, and sufficient resources. Each of these great projects strengthened our physical and scientific infrastructure and profoundly transformed our Nation” (ASG 2009: 11). One of the strongest analogies advocates for the search for a cure have historically utilized is a comparison to polio (Ballenger 2006). During the first congressional hearings on Alzheimer’s disease, Robert Butler, the first director of the National Institute on Aging (NIA), testified that “In 1935, a March of Dimes was started. In 1961, less than 30 years later, the last polio epidemic occurred, the last thump-thump of iron lungs each spring. I submit that senility could fall the way polio did, if we invest now, and I would submit that research would be the ultimate cost containment and the ultimate service. We do not have polio anymore” (quoted in Ballenger 2006: 124). Research, the rhetoric goes, leads to success, a natural progression that “gives” one hope.

Yet, advocates must deploy the rhetoric as they do because, more important, hope is required to fuel that advancement.<sup>12</sup> As an anticipatory alignment, hope can incite action; and as both the ASG and Butler stress, action is necessary because clinical research is a labor and materials intensive endeavor. As Francis Collins, director of the National Institutes of Health (NIH), informed the room of attendees at a 2014 Senate Appropriations Committee meeting, “We are not, at the moment, limited by ideas. We are not limited by scientific opportunities. We are

---

<sup>12</sup> Clinical research exists within what scholars have termed a “political economy of hope” (DeIVecchio Good 2001, Novas 2006). Hope is the affective grease that fuels the drivers of the biomedical complex (Kaufman 2015). As Carlos Novas writes: “The language of hope draws upon a similar vocabulary to that of scientific discovery: it indicates a willingness to overcome obstacles, transcend limits and explore new horizons. To have or to ‘live in’ hope means to take an active stance towards the future so that the possibilities and potentiality inherent in the present may be rendered achievable” (2006: 291). Clinical research depends upon that action.

not limited by talent. We are, unfortunately, limited by resources to be able to move this enterprise forward at the pace that it could take.” Clinical research—with its cycles of trial development and implementation, securing of funding, research subject recruitment, bodily samples collection, testing and tracking, application of possible treatments, and data collection, sorting and analysis—survives on the action spurred by hope for its potential success.

However, a hoped-for future only leads to action if it is both near enough to be imagined and yet tenuous enough to require work. Anticipation, after all, figures relationships between one’s future(s) and her present in terms of affective alignment that necessarily incite her to action (Adams, Murphy, and Clarke 2009).<sup>13</sup> An “infinite horizon,” eventual but not imminent, will not move people to act in the present—it does not demand a response. Imminence is key. When advocates talk of a cure, it is just around the corner. The possibility of success must be tangibly “near” enough that a person has the sense she, too, could partake in it.<sup>14</sup> However, despite the understanding that a cure *is* coming—and soon!—the future of a world with an Alzheimer’s cure cannot be assumed as eventual. If the future were just going to arrive, regardless, there would be little incentive to work to actualize it. Rather, the very uncertainty of a particular future’s arrival is what prompts action in the present, and in this instance, that uncertainty is created through the

---

<sup>13</sup> Anticipation, Vincanne Adams and colleagues write, is “the palpable effect of the speculative future on the present. . . . *As an affective state, anticipation is not just a reaction, but a way of actively orienting oneself temporally*” (Adams, Murphy, and Clarke 2009: 247, emphasis in original).

<sup>14</sup> Guyer theorizes this distinction between a near future and an infinite horizon in the context of macroeconomics and evangelicism (2007). She argues that a near future has been “evacuated” in favor of a more long-term future horizon. Her quotation of Hayek seems particularly compelling here: “if in the long run we are makers of our own fate, in the short run we are the captives of the ideas we have created” (412). In a sense, these groups must capitalize on people’s fear of being captive to their own inaction, of already being trapped on the path toward dementia-for-all toward which that inaction steers one.

the imagining of multiple possible futures.<sup>15</sup> The future of clinical research success is only *a* future, and as activists, policymakers, and researchers work to define the boundaries of this triumphal future, they do so in opposition to what they articulate as the dystopic potential of true failure: the “Alzheimer’s Hell” so vividly painted across the most prominent narratives. By populating a “near future” of possible crisis, those invested in the project of clinical research envision a future that people in the present can take steps to ensure does not come to pass. If the “Success is inevitable—it will come someday” narrative of scientific and medical progress is less than compelling, the invocation of Alzheimer’s as a horrible existence, one which threatens every person (and soon!), constitutes another near, generalizable, and personal future: one where dementia will affect *you*, media consumer. Only you, acting in the present, can avoid that future by acting in the present. If the rhetoric is effective, the one you hope for is, in the words of the Alzheimer’s Association, “a world without Alzheimer’s.”

### **The Deferral and Displacement of Hope**

The hopeful message of the coming cure is intentionally contagious. Families understandably embrace the promise of a cure, as the 2008 support group members did, but they can easily find themselves caught up in its promissory hype. As the web page for the Alzheimer’s Association’s clinical trials search engine, TrialMatch, implores the reader, “Don’t just hope for a cure. Help us find one.” Below this a smiling gentleman, identified as Ron Grant, TrialMatch User, is quoted: “I never had the ability to help anyone with Alzheimer’s disease until I got the

---

<sup>15</sup> Adams and colleagues write: “Anticipatory regimes offer a future that may or may not arrive, is always uncertain and yet is necessarily coming and so therefore always demanding a response” (CITE 249).

disease and participated in a clinical trial. It would be hard to overstate the importance of getting involved” ([http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)).

As both those diagnosed and family caregivers come to realize, though, the future the coming cure promises is not envisioned equally for all. Through an ongoing deferral of the future’s arrival and the displacement of intervention onto a pre-symptomatic subject, the activist and research communities make clear the future to which those living with a diagnosis of Alzheimer’s disease have been ascribed all along.

### *Deferral: The Pace of Scientific Progress*

Despite a language of hard-fought imminence when talking about the coming cure, the future of the coming cure—and the attendant hope—is necessarily one that can, time and again, be pushed a few years farther into the future. The certainty of the logic of the coming cure is in the fact that it will arrive; when that arrival will occur, however, is less certain, and the potential success of clinical research is articulated in cautiously anticipatory, continually deferrable terms. Activists remain intentionally vague, assuring success is around the corner, saying only that the day is “near.” And, when timelines are discussed, they are distant and revisable. The Alzheimer’s Association’s report, “Changing the Trajectory of Alzheimer’s Disease: A National Imperative,” offered a bold hypothetical scenario when it was published in 2010, detailing changes in the population and attendant cost of care were a treatment to become available in 2015. In 2015, the Association replaced the report with an updated version, offering projections at that point based on a treatment in 2025. There was no mention of the previous report or the shifted timetable in the press release for the new report, saying only that the report “reinforces the value of reaching

the 2025 goal set by the National Plan to Address Alzheimer's Disease mandate by the National Alzheimer's Project Act (NAPA)”

([http://www.alz.org/news\\_and\\_events\\_discovery\\_of\\_Alzheimers\\_disease\\_treatment.asp](http://www.alz.org/news_and_events_discovery_of_Alzheimers_disease_treatment.asp)).

Where advocates edge toward ambiguity, the medical community tends to more openly acknowledge the possibility of rewriting the coming cure's timetable. At a 2011 state level hearing in front of the Committee on Health Care Availability and Access, a panel including the directors of the state's Alzheimer's Disease Centers presented on the need to increase funding for dementia research. Collectively, they laid out their case, largely in terms of the overarching narrative: AD “robs people of their memories and futures; robs families of their loved ones; robs society of productive members;” it is hard on the state's economy and will only continue to be more so. Each of them then entreated the panel of representatives to increase funding for research, encourage collaborations that do so, and put pressure on the federal government to do so. As one director, Dr. A, noted, invoking the marginalization of caregiving, “[W]hile it is essential to provide care to those people that are directly affected, and to provide support for those indirectly affected, we must recognize that current treatments have limited impact on Alzheimer's disease.” He continued, suggesting that the panel implore state agencies to partner with “Alzheimer's disease research centers, the Alzheimer's Association, and other stakeholders to promote participation in clinical trials.” After their presentations, a state representative asked what researchers consider the unanswerable and funding agencies consider the key, “Do you have any idea, if we continue to move along at the pace that we are and the funding that's available, is there any time that you're going to be able to say that we'll see something? Some real progress?” The director of a different ADC, Dr. B., paused for a moment, and then

responded, “You know when I started in this field, about thirty, thirty-five years ago, every time I was asked this question, I said, ‘Five years.’ And so it’s been, uh, many times where we’ve made that projection. I think right now all we can say is that it’s real progress that’s absolutely astounding in the basic science. On the other hand, practically, we haven’t made a big difference, and that’s what we are all trying to do, working day and night.”

Dr. B’s statement explicitly describes the deferral of the coming cure—five years, then five more...followed by five more.<sup>16</sup> The periodic shifting of expectations in those shortened terms have built up to a three-decade, career-long search for the “something” the state representative references. This is the pace of scientific progress—of a slow production of knowledge and an often arduous translation process; of labs, and collaborations, and funding cycles. Without the embodied constraint of Alzheimer’s disease as lived within a particular person, the pace of scientific progress shapes a temporality of Alzheimer’s disease at odds with the pace of Alzheimer’s for families living with the condition.

### *Displacement: Cure for the Pre-Symptomatic Subject*

As discussed in the previous chapter, the opposition between care and cure hinges, in part, on a perceived ability to intervene, to act upon the Alzheimer’s disease in a way that is viewed as meaningful. An intervention only gains legitimacy as meaningful action if it alters the downward slope of decline. This is the logic within which the activity of caregiving is rendered a non-action. Yet, across the years, “cure” has been redefined to include a range of interventions

---

<sup>16</sup> Guyer’s rendering of evangelic prophetic time is notable here: “[T]he evangelical concept of prophetic time is striking as a replication and transformation of the near future as a kind of hiatus, whose intelligibility is explicitly in abeyance.”

that also fail to meaningfully address the trajectory, indeed that are not intended to do so. Rather than reversing or halting the decline, efforts toward cure and the discourses that surround them increasingly focus on prevention (catching the decline before it occurs), delaying onset (shifting the decline later in the life course), or slowing the progression (extending the decline).

Overwhelmingly, especially since several late stage trials aimed at reversing what is considered the pathology of Alzheimer's disease failed to show significant results (e.g., Mangialasche et al. 2010), the momentum of current clinical research has shifted to focus on preventing or delaying the onset of Alzheimer's disease (see Lock 2013 for a detailed discussion of this shift). As the Alzheimer's Study Group's report recommends: "As a national priority, urgently focus on developing the capability to delay and, ultimately, prevent Alzheimer's disease" (ASG CITE, 11). When these recommendations, along with subsequent ones from the advisory council who drafted the Plan, were translated to the National Plan, the "goal [became] to develop effective prevention and treatment modalities by 2025. Ongoing research and clinical inquiry can inform our ability to delay onset of Alzheimer's disease, minimize its symptoms, and delay its progression" (NAPA CITE, 7). Together, these desired interventions—the new hope of the near future—radically shift the target population from a person who has dementia to a person who *might* have Alzheimer's in the future.<sup>17</sup> As Dr. B, the ADC director, was recently quoted in

---

<sup>17</sup> In a short 2011 piece, entitled "Prevention is better than cure," neurology and psychiatry professor Sam Gandy wrote: "The best hope for therapies aimed at amyloid- $\beta$  levels, therefore, is to dose prophylactically to stop it building up in the first place. A diagnostic category of 'presymptomatic Alzheimer's disease' was recently proposed for subjects with strong biomarker-based evidence of disease but who are cognitively intact. ...Perfecting the selection of subjects and the timing of intervention could delay the onset of Alzheimer's disease substantially. A century of effort has brought us to a rational model for how Alzheimer's disease might begin, and we should not be discouraged by the prospect of another decade or two of work to settle the amyloid- $\beta$  issue and ultimately, we

an interview, “Once a degenerative disease is evident, the damage is irreversible. . . . The only realistic goal is to prevent the disease or stop its progression, and this can only happen if we understand the disease so well that we can either predict it before symptoms emerge or diagnose it in the very early stages.” No longer is “cure” about treating a person who has dementia, about “reversing” the dementia; instead, efforts for a “cure” become focused primarily on the prevention of dementia or the delay of its onset, both of which affect only those who do not yet have it. The near future of success is, ultimately, not a success for people with dementia at all.

The careful wording of TrialMatch user Ron Grant becomes more understandable: He has the ability to help *someone* by participating in a clinical trial, but he says nothing about the possibility of a cure for himself. In the world of clinical trials for Alzheimer’s, all are conscripted, but none so much as those living with AD, to the role of what Margaret Lock has termed “stoic corporeal citizens,” “those who choose to make their bodies available for the betterment of society at large” regardless of personal benefit (Lock 2013, 128).<sup>18</sup>

---

hope, defeat the illness. Prophylactic intervention to lower amyloid- $\beta$  levels is now the best hope” (S15). In her work, Lock quotes Gandy as reportedly having said, “All these symptomatic trials are 25 years too late” (2013: 216). Both displacement of cure onto the presymptomatic body and the deferral of clinical time as long as need be are clear.

<sup>18</sup> See also S. Lochlann Jain’s discussion of randomized control trials (RCT) and cancer (2013, esp. chapter 5). As she writes, “The simple yet unspoken premise embedded in late-stage cancer RCT logic holds that nearly all of the subjects in treatment trials will die. . . . [T]he RCT asks its subjects to partake in the higher calling of what the philosopher Michel Foucault might have called “collective living on”—the sacrifice of oneself for the possibility of a social group. . . . This overlay between one’s own mortality and the longevity of the society lies at the crux of the trade-offs in cancer research and treatment” (117-8).

## January 2008 (II): Tempered Hopes, Revised Expectations

A disjuncture between this temporality of clinical research and that of families living with AD tempers family members' expectations of possible reprieve from the changes they see in people living with Alzheimer's. After listening to the opening discussion among family members that morning in 2008, the support group's moderator Justin asked of those assembled:

I wonder what it's like to hear— to be sitting where you're sitting and to hear, "Oh, maybe in two years, there'll be this..." or, you know, "We're in this research study and in a year we'll have these results." Or maybe in three years. I mean, from where I'm sitting...it seems like there's always something on the horizon. There's always, I mean someone in this group is always in some kind of a study. Usually, multiple people are in multiple kinds of studies. And I'm al- you're always hearing: This thing *may* be out there. And I can't help but wonder, what's it like to sit there, always waiting for this thing...to be there.

His question gave voice to the way that families living with AD must situate and re-situate themselves in regards to clinical research, given its speculative, continually deferrable nature. They sit and they wait, oriented toward the horizon Justin invokes, which never seems to draw closer despite a preponderance of conditionally hopeful rhetoric. Justin ends his question by asking what it's like to sit "there, always waiting for this thing...to be there." As the group responded to his question, they started to map out the dimensions of the "there" where families existed, not a spatial orientation but a temporal one, a relationship between their present and potential futures.

The pace of Alzheimer's disease for those living with the diagnosis—the temporality of everyday Alzheimer's—is less forgiving than the temporality of clinical research acknowledges or allows for. Even in the brief snapshot of their earlier conversation, it was evident as Marcia asked about the treatment's potential "if you start early enough," or when Tom said that he would "jump at the chance" to try something for Holly because "[i]t's just not going to get better."

This temporality is defined by duration—how near the horizon of death is—and the movement of decline. Families often are told by clinicians or informational materials averages about eight years from diagnosis until death. As families compare the timeline of Alzheimer’s disease as they are living with it and that of scientific progress, they confront the temporal disjuncture. As Marcia described it that morning, “They’re [treatments] there; they’re coming out. And there’s a lot in, like, Phase Two studies.” She began with party-line rhetoric about the nearness of effective treatment and the progress of research, both indicated by the sheer amount of research. However, she quickly placed that purported progress in relation her family and John’s diagnosis, “So a lot is going on, it’s just not— it’s never fast enough, you know, for us in this situation.” Eddie expanded her comment, switching from a focus on drug development to a focus on his wife’s decline, “You just hope that, that—you know, like my wife is in, she’s relatively good, and you just hope that she can hang on long enough. Before it, you know, it’s—” Marcia finished his thought: “Till it gets to the point where no matter *what* drug it is, it’s progressed too far.” As both Marcia and Eddie talk, their spouses’ opportunity to take advantage of a future treatment is placed in peril by their decline. Eddie’s description of his wife as “hanging on” is not only a physicalized description but a temporal one, where one must pull the present (her “relatively good” present state) into the future. One’s ability to bring a static present into the future, however, is limited, at best. As one woman, who had been soaking up others’ advice and opinions that morning but otherwise mostly had remained quiet, spoke up, “You’ve got this hope, and then every time you see any kind of deterioration, even a little thing, you go, ‘Wait, no! Not yet.’ Because they don’t have the medicine out yet.” “It’s too soon!” Marcia exclaimed, laughing somewhat incongruously.

At some point, the future of the coming cure moves beyond the reach of the person with Alzheimer's disease. The future when their spouses' AD will have "progressed too far," that dystopic future of advocacy rhetoric, looms closer. This is the temporality with which group members understood themselves as reckoning that morning. Close to the end of the meeting that morning, Marcia spoke:

I kept hoping John was going to come back after getting sick this summer and then having a seizure. I kept hoping—because he did show signs that he was coming back, but now, in the last, you know, month or so, I've kinda just decided, you know, I think, we've tried so many things and at least I know we've tried. We've tried and we've tried and we've tried, trying to figure out his medicines and, and it's just gotten to the point where there's no more trying something and just learn to deal with what it is and we're just in a new place. And I didn't think we'd be here this fast.

Across the speech, she moved from a hope for reversal to a "new place" where "there's no more trying." This new place, the "here" at which she and John have arrived—too quickly—seems closest to what Justin was asking about. Expectations have been revised, and hopes tempered. They have tried repeatedly, and now they wait in an arrested present.

### **October 2012 (II): Constrained Hopes**

Returning to 2012, the group that October day also talked about clinical trials, although the tenor of their discussion was markedly different than that of Eddie, Marcia and the others above. The conversation was not one of, like Eddie and Tom, information seeking, one looking for possibilities, however slim, for intervention. Their resignation to the certainty of inevitable decline was closer to Marcia's in the final quotation above: "there's no more trying something."

While the meeting had drifted from Helen's opening confession through a range of topics centered around end-of-life care, Miriam, who was a forceful presence in meetings, often blunt

and off-putting, turned the conversation to more squarely confront Helen's moral dilemma, speaking haltingly: "Well, what's so very frustrating is, you know, all our- e- the problem we have we're here for will resolve. And to wish for it to resolve is either wish for a cure or to wish for the death. And that is such a negative thought." For Miriam, as for the other family members in the room that day, the realm of possible resolutions was limited within the organizing logic of the coming cure: either their loved ones would be cured, and the trajectory of decline averted, or they would die, and the trajectory would reach its endpoint. Hopes seemed limited to these two outcomes.

A moment later Tom, who back in 2008 talked of the "huge risks" he and his wife Holly would take to regain "a little quality of life," spoke up, "But none of us would want a cure, at this point. Because, because they wouldn't be able to bring the person back to where they were." Here, the re-visioning of "cure" that occurs in national Alzheimer's activism discourse clearly seeps into their understanding of clinical research and the possibility of their own hope for the future. "Unless the cure brings 'em back," Craig interjected, "If all they do is have a cure that stabilizes them, well, I don't want that." "Yeah, well, that would be an amazing thing. But there's been such damage done to the brain..." Tom voiced skepticism, which Craig then finished, "You can't imagine that would ever be reversed." Within this revised notion of cure, the "negativity" Miriam expresses about the options they have becomes clear. As Tom repeated pointedly, "That's why I think none of us in this room really wants a cure, at this point. Now maybe the earlier folks do, but we're mature enough at this point that we wouldn't want that." At a certain point in the trajectory of decline, even if one is able to set aside the protracted temporality of clinical research, cure no longer seems a realistic possibility for which to hope.

Of course, there was one more possibility that circulated through the room: an extended present of continued decline. It could be heard in the question, “How long, oh my stars, is this gonna keep going forever?” Within an extended present, people living with Alzheimer’s and their families come to orient not to the foreshortened horizon of eventual death but to the trajectory of decline that precedes it. A decline that might “keep going forever.” Although family caregivers recognized the fiction of an infinitely extended present, the specter of its possibility loomed as the more feared possible future for family—continuing indefinitely to act as your spouse’s caregiver, a role in which you are unable to meaningfully act, while they hover, waiting in a gray “zone of indistinction” (Kaufman 2005).<sup>19</sup>

Between these constrained options, hope for a spouse’s death might begin to make more sense, and Helen’s disappointment at her husband Jerry’s improvement might become a more understandable emotional response. Since Jerry’s diagnosis in 2008, the two had oriented themselves to this temporality of decline and the certainty it entailed. While at one point they may have entertained the possibility of a cure for Jerry, by 2012 they no longer did so. They knew a cure was not for them. Helen continued to act as Jerry’s caregiver, visiting him as frequently as possible. Mostly, they were waiting; as Helen said, “I was sort of on this trajectory

---

<sup>19</sup> Kaufman defines “zone of indistinction” as being “biologically alive, though only because [a person] is sustained by biomedical technology, and without signs of unique, purposeful life” (98). My use here is slightly different, referring instead to the indistinguishability of the extended present, the felt flattening of waiting that renders each moment indistinct from that which precedes and that which follows. It is a waiting that has qualities similar to the waiting Kaufman describes patients and families feeling in hospitals: “[W]aiting is distinguished by a feeling of anticipation mingled with hope and dread. The anticipation is born of incomplete understanding of a journey of uncertainty” (148). Yet, the dread Helen and the others articulate is one born of the fear that the purported certainty (of death) isn’t certain at all, and that what will replace it is the certainty of the extended present.

where he was gonna get worse?” To suddenly see improvement was not, at that point, to suggest a reversal in the trajectory, it was only to temporarily forestall it. And, as both Tom and Craig talked about, they were too far along in the trajectory (too “mature,” using Tom’s odd euphemism) to want to forestall it. The only remaining question in Helen’s mind was, “How much longer is this gonna be?”

Shortly after the October meeting, I had the opportunity to ask Helen what she hoped for, now that she found Jerry and herself in what she called a “holding pattern.” “For him or for me or for both?” she asked, before continuing, “My hope for him is that... he goes to sleep one night and doesn’t wake up.” She was concerned, she said, because he has sleep apnea, and if he fell asleep and woke up with trouble breathing, they would take him to the hospital. “Even though he has a DNR.<sup>20</sup> They’re not truly set up like a hospice situation, where they will comfort him. And so, um...” she trailed off, before turning to her wishes for herself, “I would...[crying] I would wish that I could be there. I would hope that I could be there...when he dies.” Her hopes, for both her and Jerry, concerned the possibility for a “good death.”

## **Conclusion**

As I wrote in the introduction, this chapter has been an attempt to work through Helen’s reaction of disappointment to her husband Jerry’s sudden improvement. In order to do so, I traced the possibilities for the future within the logic of the coming cure, and how families come to orient to those in their own lives. I demonstrated that, as families came to understand their lives in terms of those futures, their hopes were constrained. Such an attempt was not undertaken

---

<sup>20</sup> Do Not Resuscitate order.

to justify the reaction, but rather to try to understand how and why, at that moment—at that point, one might say, in the trajectory—it came to be her response. While certainly not every family comes to feel the way the group did that October morning, the ideological force of the anticipatory logic of cure often can override the possibility of an alternative understanding. Within the dominant logic of the coming cure, the future is written in terms of a successful intervention into the cases of Alzheimer’s disease that *might* be, but has little to do with the cases that are. For people diagnosed with Alzheimer’s and their families, that near future never comes closer, and the present state of decline just extends, shaping hopes for their own futures.

## Chapter Five—Shifting Intimacies and the Flexibilities of Family Relations

Shawna and Jonathan Johnson had met later in life, both in their 40s when they first encountered each other at the grocery store where they worked. They began dating and shortly were married, a second marriage for each. According to Shawna (with her characteristic understated manner), the marriage was “going along fine,” but then Jonathan started getting upset, his moods volatile. He would get depressed, she said, and “so angry, crazy. And Jonathan’s not an angry person.” She was most frightened by his insistence that she was having an affair. However, she was also convinced that Jonathan’s condition was more than depression or paranoia, that something was wrong with his memory. “Like at Easter,” she told me, “I just remember he couldn’t tie his tie. He had a really hard time doing it.” Or driving directions; he would ask for her help navigating the familiar streets of their suburban neighborhood. Eventually, they went to a neurologist, and at the age of 55, Jonathan was given the diagnosis of early-onset Alzheimer disease. Three years later, Shawna and I sat on their back porch, sipping lemonade and talking about the two of them, his dementia, their relationship, and their family.

I asked her how things were going at that point, and she told me that the days when they were active and did things together were the best. Summers were good because he could work out in the yard or play with the dog or go for walks; winters, in contrast, could be long, with little to do. The conversation moved in another direction for a while, and then, at one point, Shawna said, “It does feel like, well, the marriage is over. You know, the marriage part is over. I feel like, like he’s a kid. ... You know, *but*, this is what—you tell em how to tie their shoe, they’re gonna learn how to tie their shoe. But this is like, you’re telling ‘em to do something and they’re not gonna do it.” She laughed quietly, “They’re going down, they’re not learning anything anymore.

It's not like you're training a child and they're gonna get better. It's like you're trying to help 'em—like get dressed and—it's very sad. That he can't get dressed himself that much anymore. You know, puts stuff on backwards, inside out....”

In this chapter, I examine the near-ubiquitous practice in which caregiving spouses, at some point during the course of the illness, reframe their partners as children. Typically, scholars interested in the care and personhood of the person with AD condemn the conceptualization of a person with Alzheimer disease as childlike as contributing to that person’s social death (e.g., Kitwood 1993, Sabat 2001). However, the logic of those arguments relies on an ideology of the child that sees children only as dependents, non-agentive, powerless, and objectified. In contrast, I argue that spouses often use surprisingly flexible understandings of kin relations to make sense of the changes the relationships are undergoing. They are able to continue to understand the person for whom they care within a relational context as a part of the family. And, in doing so, rather than hastening the person’s social death, they create a temporary space within the trajectory of decline to maintain a recognizable relationship of care.

### **The Threat of Infantilization**

Across my research, Shawna was hardly alone in her sentiment. At a certain point, many family caregivers spoke of the person diagnosed with Alzheimer disease as “like a child.” These statements strike the ears—they did mine, at first, certainly—as harsh, and as potentially harmful to the person who is being called child-like. In short, they sound like statements of what, within the literature on care and aging, is discussed as “infantilization,”

Infantilization has a history in both research on aging and, specifically, in studies of dementia. In the late 1960s and early 1970s, discussions of infantilization as a demeaning social process began to appear in gerontological literature (Gresham 1976). In dementia studies, infantilization was most clearly articulated through the work of Tom Kitwood, the social psychologist who started the discussion of person-centered care (1993, 1997, also see chapter 2). Across these literatures, caregivers who infantilize—whether professionals, spouses, or adult children—are understood as problematically interpreting their own care relations as similar to a parent (caregiver) caring for a child (the elderly person). Through this parent-child lens, the caregiver comes to act toward the older person as they would toward a child. Common examples of infantilizing interactions include feeding, using a “sing-song” tone, referring to the person as “girl” or “boy,” imposing rules on the person without feedback from her, and using dolls or other toys to occupy the person. Kitwood uses the example: “Mr. D has always been rather helpless at home, with his wife being ‘strong’ and motherly. Now he is extremely confused. She speaks to him in exactly the kind of voice she would use with a three-year-old. When he tips over the milk jug, she smacks him lightly and says, ‘Jack, that was a naughty thing to do. If you behave like that, I won’t let you have tea in the sitting room anymore’” (Baldwin and Capstick 2007: 38).

In the context of dementia, Kitwood described infantilization as one element of his malignant social psychology. As discussed earlier, part of Kitwood’s project was to articulate a model of dementia that accounted for the social processes that exaggerate and contribute to the cognitive challenges a person diagnosed with dementia already experiences. Kitwood conceptualized infantilization as a “more extreme and persistent form of” disempowerment, another element of malignant social psychology, “but accompanied by messages, subtle or

otherwise, that the dementia sufferer [*sic*] has a mentality and capability very much like that of a young child” (38).

The argument across these is that treating an older person like a child is harmful to their sense of self, continued independence, and well-being. Infantilizing treatment fails to account for the lifetime that an adult brings to a moment of interaction, erasing years of experience and the accumulation of a self (Sabat 2001: 323). Researchers have demonstrated that, by taking over processes such as feeding or brushing one’s teeth or making decisions, a caregiver can actually enfeeble the person with whom they are interacting. Often, this becomes a self-fulfilling prophecy of unlearning, what has been termed “learned disability.” These infantilizing interactions, as they sap a person’s dignity, will, and ability not only contribute to a social death but also can be seen as hastening a biological one. As Jaeger and Simmons wrote in *The Aged Ill* (1970):

. . . treating the aged patients like small dependent children is to be deplored and opposed. Such treatment is viewed as adding insult to injury, being an offense to one's self-esteem as an adult, and doing no one any special good. Indeed, it tends further to promote the regressive traits themselves, makes for increased dependency, destroys self-reliance, intensifies false feelings of helplessness, and mars as well as undermines any remaining sense of strength, power, and adult dignity. (48, quoted in Gresham 1976: 208)

Ethicists and gerontologists thus argue that infantilization dehumanizes the person with AD. It does so by striking at the core of who a person is, erasing their history and all that makes them uniquely *them*. It turns them into an object, something only to be tended to and cared for, but not something that one has a relationship with. In doing so, it damages their dignity and sense of who they are. They can no longer act in or on the world around them. This is a crucial critique of the power dynamics that can arise between caregivers and those to whom they provide

assistance, and this work has done much to advocate for a restoration of the dignity not just of those living with Alzheimer's, but of all elderly persons who find themselves the recipients of caregiving.

The roots of this critique lie in the institutional setting of long-term care. Kitwood's example, then, of the wife who chastises Jack for tipping the milk jug may seem out of place. As he writes, "I have deliberately laid aside the effects of institutionalisation, *per se*, with its well-known tendency to deprive individuals of their former identity, and to reconstruct them within the institutional frame. Of course, the processes that I have described do occur within long-stay institutions, but they are certainly not specific to them" (Baldwin and Capstick 2007: 39). Much of the critical gerontological literature on caregiving makes a similar move, rendering the ethical worlds of both professional and family caregivers as one and the same, as though the home were simply an institutional care setting stripped of its institutionality. Historically, the gerontological critique of institutional care merged with the literature on family caregiving, such that the ethics of caregiving were developed from observations and assessments of professional caregiver-care facility resident interactions, rather than family interactions. As such, this research and the guidelines it has produced, rooted in that professional care environment, often transfer imperfectly to the family milieu.

### **Activities of Daily Living: Rendering Spouses as Children**

Shawna's description of Jonathon as "like a child" in response to my question about how things are going is striking, in part, because of how she describes his childlike nature. Her descriptions are about activity, especially about dressing oneself: Jonathon had trouble tying his

tie, he puts his clothing on backward. There are, of course, many ways to answer the question of how one is doing. Without fail, though, as I would ask families the question over time, their answers and illustrations would be in terms of activity—the diagnosed person’s ability to complete certain activities and need for the family caregiver’s assistance.<sup>1</sup>

One winter evening, for example, I was having dinner with Michael and Gregory, a couple who had been living with early-onset Alzheimer’s disease since Gregory’s diagnosis in 2004. As was our routine over the course of my research, I would come to their condominium in the afternoon, we would have coffee and cookies, which Michael always would assure me Gregory had chosen, and then leisurely prepare and eat dinner, talking late into the evening. This visit, with the holidays approaching, we also were baking cookies; Michael and Gregory enjoyed the tradition of baking and distributing several dozen cookies of different varieties to friends and family. We made two different kinds, oatmeal and a family recipe for apple cookies, with all of us involved in the baking process. Across the evening, I noticed that Michael was asking Gregory to do a lot—find spices in the drawer, measure out flour, roll precisely shaped balls of dough, and put ingredients and dishes away as we were finished with them. The treatment seemed in contrast to Michael’s usual interactions with his spouse, as he typically was attentive to moments when Gregory needed assistance, while also supporting Gregory’s ability to do things himself in ways that were noteworthy among families with whom I worked.<sup>2</sup> At one point, as Gregory struggled to find the empty spot for the bottle of ground cloves amid a drawer full of

---

<sup>1</sup> This calls to mind Bridget’s discussion of whether she or Maria, the home health worker, was the caregiver and how that hinged on the activities they had to do.

<sup>2</sup> Although Michael and Gregory were not married in a civil or religious ceremony—and chose to not to go through a civil marriage ceremony even once the option was available—they considered themselves married and would use the word “spouse” to describe their each other.

identical, black-topped spice bottles, Michael turned to me and noted that his treatment of Gregory had been strategic. He raised his eyebrows, saying that he'd been pushing Gregory to demonstrate to me Gregory's current abilities. Michael and I both noted that Gregory's fluency in their kitchen and condo was becoming compromised.

In many ways, as discussed in chapter two, as families learned to see Alzheimer's disease and family caregiving through activity and came to understand themselves as living with Alzheimer's, they began to describe themselves and their relationship through the vocabulary of activity. Given the medicalized stress on activities of daily living (ADLs), viewing the people and relations of family through the lens of activity makes sense. And as the person diagnosed with Alzheimer's changed more dramatically, requiring more care, the series of activities referred to as "basic ADLs"—dressing, eating, mobility, and going to the bathroom—became the focus of families' attention and caregiving labor.

Caregivers increasing participation in daily activities coincided with their description of the diagnosed person as increasingly like a child. Indeed, ADLs often are the same tasks which with children need assistance. The parallel is not coincidental. Sidney Katz, the physician who developed the original Index of Independence in Activities of Daily Living scale in the 1960s, wrote that, the scale was "developed independently," the terms used were "strikingly similar" to those used in discussions of skill acquisition and child development in pediatric texts (1963: 917). He goes on to write:

The data presented in this paper indicate that the pattern of recovery from a disabling illness in later life parallels the primary development of function in the child. It might also be hypothesized that, just as there is an orderly pattern of development, there is an ordered regression as part of the natural process of aging. It seems reasonable that loss of function would begin with those activities which

are the most complex and least basic, while those functions which are most basic and least complex could be retained to the last. (918)

Psychiatrist Barry Reisberg drew this parallel explicitly into Alzheimer's research, proposing "retrogenesis" as a descriptor of the life course of a person diagnosed with AD.<sup>3</sup> He and colleagues defined the term as "the process by which degenerative mechanisms reverse the order of acquisition in normal development" (Reisberg et al., 1999: III/28). They traced what they saw as evidence of clinical, physiologic, and neuropathologic "degenerative mechanisms"—a loss of functional ability; a return of "neurologic reflexes known as 'primitive reflexes' or, alternatively, as 'developmental reflexes'" (III/30); and, at the level of neuropathology, cortical atrophy and myelin loss. Moving from the gross, externally observable, and social to the molecular, internal, and ostensibly biological, they plotted the elements of increasing degeneration along a stage model that progresses from preclinical to severe stage dementia, mapping a trajectory that is, as they write, "as clear and consistent as, and, in many ways mirrors, the normal maturational course of human development" (III/28).<sup>4</sup>

---

<sup>3</sup> Reisberg is the current director of the Fisher Alzheimer's Disease Education and Resources Program at the NYU Langone Medical Center.

<sup>4</sup> The concept grew out of what Reisberg and colleagues initially charted in their development of the Functional Assessment Staging of Dementia scale (FAST), one portion of a Global Deterioration Scale (GDS; Reisberg 1988):

As the disease progresses, individuals with AD lose the following sequence of abilities. First, they lose their ability to hold a job (FAST stage 3), and then become unable to manage their finances (FAST stage 4). They cannot select appropriate clothing for the occasion (FAST stage 5), put on clothes without help (FAST stage 6a), shower without help (FAST stage 6b), or toilet without help (FAST stage 6c). They become unable to control their urine (FAST stage 6d) and their bowels (FAST stage 6e). At later stages in the disease, they can only speak only five to six words (FAST stage 7a), then just one word (FAST stage 7b). They have lost all other abilities and are only able to walk (FAST stage 7c), then simply sit up (FAST stage

As diagnosed persons become increasingly dependent on the assistance of family caregivers to complete these daily activities, caregivers shift not only their view of their diagnosed spouses, but also their conception of themselves. It is not just the relational position of the person diagnosed with AD that shifts; caregiving spouses also must make the transition from a relation of partner to one of parent, a process that requires a great deal of conceptual work.

Joanne and I were once talking about the care she provided for her husband Alan:

But today, I had to be like, “Brush your teeth.” So he walks in the bathroom and he just doesn’t know really what to do. “Okay, here’s your—” (you know) “—your stuff is here.” And he can brush his teeth by himself. And then I’m like, “Okay, go in the closet and take your shirt and shorts off.” He walks in the closet and he just is standing there. You know, he just doesn’t really know... what to do? ...Even if everything is out, he just doesn’t know... what to do.

As these activities become common interactions, the caregiving spouse begins to feel like a parent. A moment later after she told me about dressing and brushing teeth, Joanne described feeling like Alan’s “mom, making sure he’s taken care of.” In his blog about their life with Alzheimer’s, Michael has written about feeling like Gregory was “becoming more and more of a child and me becoming more and more of a parent,” as he describes mishaps in dressing and moving about their home.<sup>5</sup> Even though she didn’t specifically use the word “parent,” Shawna implied feeling like one as she talked “training” a child and the difference between that and her interactions with Jonathon.

---

7d), then only smile (FAST stage 7e), and finally only hold up one’s head without assistance (FAST stage 7f). (Rogers and Lasprilla, 2006)

<sup>5</sup> “Before you arrived, he wasn’t sure what else he needed to get dressed and looked quite dapper in his black shoes, sox [sic], underpants with black belt, and undershirt. Try living your life like that:-)”

## **The Shifted Intimacies of a Spousal Relationship**

While activities of daily living provide a vocabulary for describing the changes rendered as one lives with Alzheimer's disease, it is an anemic one. The evaluation of a person's health in terms of whether she can lift a spoon to her mouth herself collapses the multi-faceted nature of "health" and flattens the complexity not only of the shifts wrought by AD, but also the relations such shifts entail. Through the process of learning to conceptualize moments, actions, tasks, and interactions as "activities of daily living," families come to use ADLs as a shorthand for marking a whole range of changes that encompass far more than one's ability to complete tasks. In this way, the concatenated activities that compose dressing for Easter or brushing one's teeth can be used as an illustration of the understanding that the husband-wife relationship no longer exists.

The language of ADLs casts relationality within a language of lopsided, pathologized dependency and misses a crucial aspect of spousal relationships: intimacy.

Intimacy is a textural quality of caregiving activities that adds flesh to the bones of ADLs. In discussions of caregiving and care work, the labor of care work is described as intimate (e.g., Boris and Parrenas 2010). Most often, these discussions of intimate labor revolve around the quality of the work itself—as involving more than one body, often in close contact; as entailing dependence (or interdependence, especially when the labor is commodified); as often focused on tasks deemed unpleasant, washing bodies, changing linens, dealing with bodily waste. Starting with the activities themselves, the very intimacies of the acts through which families come to know not only Alzheimer's disease but the person diagnosed with it strain the potential for understanding that person as spouse. A spouse, within a normative discourse of able-bodiedness, does not need help dressing, bathing himself, eating, or going to the toilet. A spouse, the

discourse goes, performs such activities independently. While such a discourse is obviously problematic, its strands wend through families' articulations of their relations. It is when a person must help her spouse with these actions that she becomes caregiver, and her spouse, a person diagnosed with Alzheimer's. Often, for my informants, occupying these new roles forecloses the possibility of also being spouses. The rigidity of the relation of spouse makes it a mutually exclusive affinity. Intimacy provides a useful lens for understanding the ways in which people view the dyad of the caregiver and person diagnosed as antithetical to the spousal dyad.

Intimacy further widens the scope of the discussion beyond activity. Lauren Berlant opened her introduction to the edited collection on intimacy with these words:

“I didn't think it would turn out this way” is the secret epitaph of intimacy. To intimate is to communicate with the sparsest of signs and gestures, and at its root intimacy has the quality of eloquence and brevity. But intimacy also involves an aspiration for a narrative about something shared, a story about both oneself and others that will turn out in a particular way. (1998: 281)

The focus of intimacy on expectations in her rendering resonates with the discussion in the last chapter.<sup>6</sup> The uncertainty of the aspirational, of a focus on the future, adds to a colloquial understanding of intimacy as something that is acquired over time. In this way, intimacy is not only about a life shared, but one planned. Across our discussions, Joanne described a loss of intimacy with Alan in the former regard, as a shift in a life shared: “When you know so much about somebody, that's the intimacy that you have. I mean, I can remember—I don't know what he remembers. ...Or how he feels. I mean, he knows who I am...I think. He'll ask me things like “Where did we get married? When did we get married?” Things like that. So it's almost like he's

---

<sup>6</sup> Also, her emphasis on a communicative act is noteworthy, given the importance of communication in the US imaginary of marriage, in which it is understood as a critical part of both building and maintaining the spousal relationship.

forgetting, you know, our life together. So it kind of removes the intimacy.” Other times, however, when talking about the ways the relationship had shifted, she focused on the plans they had made for their retirement years, not what they had done, but what they were going to do, the designs on the future they had spent their life crafting. She talked about how she thought she would have some years at home alone after retiring from teaching, and that when Alan retired, they would travel. She talked about their children and grandchildren. About what they had always imagined that time would look. Yet, here they were, with a life that they “didn’t think would turn out this way.”

Intimacy, as Joanne presented it, stressed the shared quality of her and Alan’s memories and expectations. Viviana Zelizer discusses intimacy as “particularized knowledge received, and attention provided by, at least one person—knowledge and attention that are not widely available to third parties” (2005:14). The distribution of these knowledges and attentions across persons, she writes, entails relations of trust. In Joanne’s estimation, the loss of trust engendered by a shared knowledge of their past removed the potential for intimacy. She didn’t know what he remembered, or felt, if he knew her. The implications for such a dissolution of trust extend from their relationship to Alan’s person. A moment later, Joanne said, “You know, like when you’re forgetting about what you had...I just...I...he’s just not Alan. He’s not the Alan that I, you know, married.”

Across their discussions, family caregivers also stressed another aspect of that mutual trust: the shared interdependence of the relationship. That is, family members noted not only the shift in the diagnosed person’s independence but also the change in their ability to provide support to others. As noted above, becoming a caregiver was discussed in terms of assistance:

laying out clothes for a person, or reminding them to wash their hair, or helping them use the toilet. However, it also was articulated as not being able to ask the person diagnosed for help—with running a quick errand, or planning a trip, or deciding about retirement savings. As much as the person diagnosed became more dependent, the person who assumes caregiving responsibility must become less so. The trust in mutuality dissipates.

Intimacy in a spousal relationship also involves sex. The potential for sexual relations is a defining feature of the marriage relation, one that can shift dramatically as a family lives with Alzheimer's disease. Talk of sex often is rare among families in situations like support groups or clinic visits. Among the families with whom I worked, it wasn't necessarily a topic avoided as we talked, as much as it seemed one strand of intimacy among many, as outlined here. When it did come up with the families with whom I worked, people talked about it as an issue of consent. Perhaps most notable is the story one man related in support group about the end of sexual intimacy with his wife. In the midst of intercourse, he became aware that his wife did not know what they were doing. To continue having sex, he felt, would be wrong, as she was unable to willingly enter into the activity (an activity interestingly left off the ADL list). Along with consent, the potential for sex hinged on recognition. Joanne thinks Alan still remembers her, but she's not entirely sure what he has forgotten. For family caregivers, the intimacy of the sex act was not simply about the bodies or the actions, but about the acknowledgement that these actions were done with the body of a long-beloved partner. Without that recognition, the intimacy lacked emotional resonance or, perhaps worse, felt menacing.

As family caregivers express feeling more like parents, they often also discuss feeling that, as Shawna said, "the marriage part is over." The recognizable ties of a marriage relation no

longer appear as such for the marriage partners. Joanne's words during our conversations were remarkably similar, as she talked about "the husband-wife thing" as a relationship "of the past."

This loss of a spousal relationship is, in part, due to a shift in activities, and in part, due to the shifting intimacies of a changed relationship. Intimacies are altered in ways that make the relationship that remains unrecognizable to family members as a spousal one. Not just sexual intimacies, but intimacies of a life shared and remembered, of knowing another person so well, and of planning a future together. All these help to make a relationship feel like one between spouses. As these ways of relating are increasingly less possible, the relationship itself becomes less possible to maintain.

For scholars concerned about infantilization, this discourse of spousal loss is seen as a primary dehumanizing threat. The fear is that, in the absence of a grounding spousal relationship, family caregivers will isolate the diagnosed person and come to treat her without the dignity her humanity engenders. Further, as the spousal relationship becomes less recognizable to family caregivers, they can easily begin to render their diagnosed partners as non-actors. Recall Kevin discussing feeling "invisible" to his family (see chapter three), or as a woman in the Memory Clinic support group once put it, feeling "like I'm an afterthought." The dangers of social death are legitimate. Rather than contributing to that dehumanization as they refigure their relationship as parent-and-child, however, I argue that family caregivers actually are doing work to mitigate it, working to make sense of shifting family relations, roles, intimacies, and daily lives as they do so.

### **Alan and Joanne: Complicating the Parent and Child Relationship**

Understanding caregiver's work to live with Alzheimer's and the changes in the possibilities of relationality it entails requires a more expansive conceptualization of kinship. Caregivers are not, as previous scholarship would suggest, limited to a binary choice between the relational terms of fully engaged spousal relationships or socially isolated and dehumanizing parent-child relationships. Instead, they draw upon a fuller range of kin relations to make sense of the changes they are experiencing, improvising hybrid forms of relationality in an attempt to continue their projects of family-making.

When she talks of feeling as though Alan is a child, Joanne says she feels like his "mom, making sure he's taken care of." Elsewhere, she talks about thinking she was done with "all the kid stuff" after her children were raised. It is no coincidence that the parent-child relation was invoked most often by women who were in the position of acting as family caregiver for their spouse. The parent-child relation, as family caregivers came to speak of it, drew upon the well-elaborated discourse of the importance of motherhood (e.g., Kittay 1999, Ruddick 1989). In contrast to a dehumanizing relation, family caregivers conceptualized the mother-child bond as paradigmatically caregiving. More, Joanne did not talk about or enact her relationship with Alan as though it were only one of parent and child. Rather, the relationship was a blend of spousal moments, connections, intimacies, and enactments, and those she felt resembled the interactions between her and her children.

For example, one morning in late June 2011, Alan, Joanne, and I were finishing breakfast. It was a morning typical of the several I spent with them, remarkable as a snapshot of ordinariness: Joanne moving about their kitchen, flitting between the morning newspaper,

cooking breakfast, and talking with Alan and I; Alan working his way through breakfast, interjecting a comment—often amusing—or question when possible between Joanne’s stories; I listening, scribbling in my notebook, asking questions.

“Alright, Alan, let’s go get you dressed, okay?” Joanne asked, grabbing his plate, which he had cleared of its scrambled eggs with summer vegetables and toast, coffee cup, water glass, and cup now emptied of its pills. He pushed his chair back and stood, stretching and then moving off in the direction of their bedroom at the other end of the house’s ranch layout. While they were out of the room, I listened as she helped him. I could hear her reminding him to brush his teeth, directing him to his clothes laid out on the bed, and thought back to the conversation when Joanne talked about feeling like Alan’s “mom.”

In a few minutes, Alan came out of the bedroom, and we stood together at the kitchen windows, chatting about a picture that hung in their hallway.

“Okay, let’s go,” Joanne said as she entered the kitchen, grabbing her water bottle from a cabinet and popping it under the spout to refill it. “Alan, your shoes—”

“I was showing him...,” Alan interjected, gesturing toward the picture he was still facing.

“You were telling Aaron about the picture?”

“Yes,” still smiling.

“Good! Okay, your shoes are in the back closet,” she turned back to her task-at-hand, stressing the last two words in a way that nodded toward her career as a fifth grade teacher. Alan headed off to find them. After a moment, she finished filling her water bottle and headed out into the entryway where Alan was putting on his shoes. “Alright, you find your shoes in the back closet?”

I followed as Alan made a comment just under my range of hearing, and Joanne responded, “I know, I put them away every night. I fool you, Alan!” He jokingly growled, and they both laughed. “What a terrible sound you’re making!”

“It helps.”

“Helps? What are you trying to do?” I rounded the corner and found Alan trying to fit a shoehorn—an extended one that allowed him to stay standing—into his left shoe with his foot already mostly in it, his heel smashing the shoe’s.

Joanne was kneeling in front of him, “It’s the wrong way, honey, here.” She held the shoe and reached for his ankle. He appeared unsure as to how to help her help him. “Well, here...take your foot outta there for a second.” He slid his foot back out of the shoe, and her hand still on his shoe, she reached for the shoehorn and guided its rounded tip against the back of the shoe’s heel. “Okay, *now*—” he slid his foot right into the shoe “—how’s that?”

“That was slick,” he answered.

In a moment that spoke to their shared lives, she started, “Two hand are better than...,” and they both finished, “None!”

As they go about the morning together, a complicated, blended relationship emerges, comprising both spousal and parent-and-child elements. Looking at the events of that morning, the activities of daily living with which Alan requires some assistance are clear: cooking breakfast, which used to be a meal he enjoyed making, and cleaning it up; brushing his teeth and dressing; and putting on his shoes. The relationship has overtones of a parent-child relationship in the way that Joanne helps him with these—the unquestioned cleaning up of his dishes, the anticipatory laying out of his clothes, the instructions on where to find his shoes. As Joanne and I

talked about their spousal relationship over our many conversations, this sort of caregiving activity was not how she described it (although, of course, many spouses *do* do exactly that kind of tending to); rather these were the moments of “kid stuff” to which she referred.

Yet, Joanne and Alan also connect in multiple ways. Joanne often talked about food as something that Alan still enjoyed, so their meals were moments where she was attentive to that pleasure. Fresh summer vegetables, grated cheese, and scrambled eggs were an opportunity to engage in that enjoyment, to provide for it. We all were engaged in a far-ranging conversation across the morning. And although Joanne often clarified Alan’s comments, as she helped him finish his sentence, she always included him—it was the three of us, not just her and I with Alan at the side. And Alan was an active participant in the relationships that morning—both with Joanne and myself. He openly enjoyed the food; he commented within conversations; he talked with me about the picture in the hallway and joked with Joanne.

It was the interaction with the shoe, however, that struck me most that morning. I came around the corner, and she had knelt at his feet. She held his foot, so gently, guiding it, the shoehorn, and the shoe, aligning them with Alan. The activity itself was, perhaps, not one that made sense within the spousal relation as Joanne and Alan understood it. It likely made more sense in the context of a parent-child relationship. It was a moment I could imagine Joanne had with her two children as she dressed them when they were younger, to go to school or out to play in the snow. And certainly when Joanne would discuss such moments, a parent-child relationship was the way she talked about it. And yet, around the edges of that activity, in the careful touch she used, the way they joked, laughed, and smiled at each other, hints of her spousal relationship

with Alan could be seen. It was a moment of connection, of relating, a humanizing moment for both of them.

That morning with Alan and Joanne was initially what started me thinking about the potential of a changed, but still familiar relationship. He was so dependent upon her to work through the steps of getting ready, and that dependence seemed childlike. And yet it never seemed “infantilizing” or “dehumanizing” to me. Rather, across the moments of that morning and the activities that composed them, who Alan was was reaffirmed by Joanne, and the relationship was formed as they interacted with each other across, employing different kin relations as the situation demanded. Through all of this, Alan was continually humanized, in large part because Joanne continued to think of him as Alan, as her spouse, and as family, even as she also began to think about him through the relational lens of child.

### **Craig and Lisa: The Gendering of Caregiving Relationships**

I first met Lisa Donnelly, whose husband Craig would tell me that the caregiving actions he took on “made no difference,” in early 2011. She had been diagnosed with early-onset Alzheimer’s disease seven years earlier, at the age of 61. A few years before that, she had complained to her husband Craig that she “didn’t feel as sharp as she used to.” She had been working at the local library, and the library director called Craig because she was concerned about Lisa—she was having trouble remembering where to find or reshelv books, how to conduct searches, what daily tasks needed to be done. Lisa went to her primary care physician, and eventually to a memory clinic, where she was diagnosed. For a few years, Craig worked to care for her at home, first by himself and then with the assistance of a home health worker, Geraldine.

When Lisa fell in the shower as Geraldine was assisting her, however, Craig decided that he “could no longer safely care for her at home,” and she moved to a long-term care facility a short drive from their home.

Craig talked about his caregiving role as one to “provide and protect,” in keeping with how he viewed the commitment he and Lisa made to each other when they were married. Once, during a conversation about what he thought caregiving was, he mused that:

in many respects, when [Lisa] and I got married, we became caregivers of each other. You know if you stop to think about it, that’s how life works, that’s how marriages work. You become a caregiver for each other as you go through life experiencing the joys and the pains of kids, and all of that. You support each other as you go along. And so that way, you could say the role of caregiver starts at a very early age. Much before we even realize it, that we’re caregivers. Okay? And, if you accept that role and you work together to overcome whatever difficulties you have and you go on in life, you know? Hopefully when you reach the stage that [Lisa] and I are, that you’re prepared to take on even a more demanding caregiver role.

Not that he thought he necessarily was good at all of it. He talked of the strength of his commitment: “You don’t bail out halfway there, you know?” Even when he found himself confronted with tasks he found unpleasant:

Even though those are not my strengths, that doesn’t mean I didn’t try to do the best I could with that. And, I would sit here many times on Saturday, and I would know that it’s time to take [Lisa] to the bathroom, and I dreaded doing that. Something I didn’t like to do, but...she can’t sit there with wet pants. Okay? So we’d go into the bathroom, and I’d change her, and sometimes she would go and sometimes she wouldn’t. I still would do what I could do. That didn’t mean that I, I liked it or anything like that, but I just had to do it.

He also talked about his his ability to provide the things Lisa needed that he could not do himself. To his mind, his professional work had made it possible to hire Geraldine and to find a good care facility for Lisa when the time came. He saw this as a means to “compensate for my weaknesses”:

As an actual caregiver—physically taking care of [Lisa], bathing her and dressing her—even when she was home, [Geraldine] did a much better job than I ever could do. That’s just, that’s just who I am. It’s like my housework: I can clean the house, but I don’t dust. . . . I just can’t do it. And as caregivers, some things you can do, and other things you just can’t do. For whatever reason, it just doesn’t work. And, in my case, I found people that could compensate for my weaknesses. Okay? And I was fortunate enough to find them, and fortunate enough to keep them for as long as I have.

As he spoke, he circled around the idea that Geraldine was better at the tasks of caregiving, the intimate work of care, than he. Voicing a gendered ideology of care that was overwhelmingly popular among his generation (and still, certainly, is dominant), he attributed it to the fact that she was

female, and I’m male. And we are different. There’s a difference in females who act as caregivers than males who act as caregivers. And I think part of that is the maternal instinct of, you know, of bearing children. And in many cases, when children come into the house, the mother takes care of the kids. Today’s society . . . my youngest son has taken a bigger role than what I took with raising the kids. And I think to a great extent that’s true in our society today. I come from the old school, okay? And I think part of that is just the difference between males and females and maternal instinct, and the kid gets sick and he wants mommy, he doesn’t want daddy. Why is that? Because of just the way she has treated them and cared for them . . . I think it, it provides a different type of care. A much more caring care. Based on myself. You know, as I indicated, there were certain things that I did, but I didn’t do as well. As what Georgina did. Doesn’t mean I didn’t try; they just do a better job. And I accept that.

Craig didn’t speak of Lisa as a child, perhaps because, as he says, he thinks of his wife as raising the children so the parent-child framework is not as meaningful. Instead, he continued to view his work as caregiver through the lens of his marriage, as part of the commitment he made. The medicalized caregiving tasks of basic ADLs were, as he discussed them, also gendered—it was a maternal instinct that made Geraldine better at helping Lisa use the bathroom or take a shower. Other male caregivers with whom I worked expressed variations of this ideology, often talking

about how, as they began to cook more or their role taking care of the house increased, they felt as though the family roles of husband and wife had switched.

Yet, the texture of his daily interactions with Lisa, what their relationship actually looked like, complicated this gendered rendition of caregiving he gave. At the time we met, Lisa could no longer walk. She spent most of her day in a wheelchair or in bed. Occasionally she would open her eyes or squeeze your hand, if you were holding hers. He continued to employ Geraldine, who kept Lisa company, helped with her daily needs, and often helped the care facility staff with others, too. Craig visited Lisa every day for a few hours around dinnertime, spending time with her in the care facility's common room watching television with Lisa or in her bedroom, reading as she lay in bed or perhaps talking with her about his day. As the staff prepared dinner, he would bring Lisa to her table and start getting her food, or help to gather the other residents, or some nights sit and talk with the residents and their family members who were also seated at the table with Lisa. He would cut her food and help her eat it, and afterward, he would help her to her room for the night.

Several times, I went with Craig to visit Lisa. Over time, her eating changed—meals in the dining room moved to meals in bed, small bites of food changed to liquids only. Craig would come into Lisa's room and greet her, kiss her on the forehead and ask how her day was. He would sit and talk with her for a time, telling her about his day and talking with me while he drank a cup of coffee. When the staff started serving meals in the dining room, Craig would go get Lisa's food and bring it back to the room. Her food at this point was only liquid—blended soups, vegetables, and other soft foods, along with water or juice. Lisa was at the stage in the disease where swallowing became difficult. The reflex that makes a person swallow isn't always

triggered by liquids, and she did not consistently know or remember to swallow. In response, her liquids were thickened with an additive to help trigger the swallowing reflex. I would watch Craig as he tested the thickness of each food or drink, scooping a small bite up with a spoon and eating it. At the same time, he would test its temperature and taste. He would go back to the kitchen to make adjustments, and only when satisfied would he sit down to feed her.

The attention with which he tended to her as he fed her did not fit neatly with his claim that he outsourced much of the close, intimate work of caregiving. As he worried over the taste and texture of her dinner, as he talked to her, telling her what each portion was while he fed her, as he touched the spoon gently to her lip to help her know to open her mouth, he was doing work that seemed to more closely approximate the “much more caring care” he described as inherently maternal. Although he did not articulate it as such, the relations enacted as Craig tended to Lisa were much more than the gendered “provide and protect” he discussed. Through Craig did not name them, in response to the shift in Lisa’s needs, he had expanded his caregiving relationship with Lisa.

## **Conclusion**

The relationality of families are complex, as Joanne hinted at when she described hers and Alan’s relationship not as gone but as changed, “The dynamics have changed. Before we were like...partners, now we’re just...I mean we’re still partners, but it’s a different kind of relationship.” As family caregivers invoke the relation of parent and child, they make use of a parent-child framework is markedly different from its deployment in institutional settings. Here, the critique of infantilization does not adequately describe the full complexity of family

relationships. Those who write about infantilization see the positioning of someone as a child as an assertion of power and dependency. They see it, as earlier Kitwood's description makes evident, as an evaluation by the caregiver of the diagnosed person's capability. Yet, these accounts fail to recognize that parents and children are kin relations. They are both bonds of sociality and the means for making those bonds comprehensible. Within the family, kin roles are tools of recognition, and while attributions of a child-like nature to diagnosed family members in moments of frustration can have precisely the effects Kitwood and others discuss, they also, in other moments, can render familiar for family members a relationship that no longer feels that way. Thinking of a person with AD as a child can be humanizing, affirming the person's humanity and allowing a family caregiver to continue a relationship that looks and feels caring and familiar. In this way, Shawna's ordering of a Coke for Jonathon at dinner does not negate his ability to choose, but rather honors the fact that she knows it is his favorite. Moments such as this become not examples of dehumanizing infantilization, but interactions of humanizing relationality.

There are, of course, limits to the flexibility of these reworked relationships. These limits are what Shawna is referring to when she says, "They're going down, they're not learning anything anymore. It's not like you're training a child and they're gonna get better." The parent-child relationship ultimately is understood as one based on development, a trajectory of growth, learning, and increased independence. And people living with Alzheimer's are on a different trajectory, one of deep forgetfulness, loss of bodily control, and increased dependence. As these trajectories diverge, a caregiving spouses' ability to continue to see the person with Alzheimer's as a child is strained. While caregivers may continue to define the activities as something a

parent would do for a child, the relationship no longer seems infused with the full complexity of interaction that a parent-child relationship can have.

## Chapter Six: Forgetting the House: Making and Unmaking Families and Homes

One snowy afternoon in December, Joanne Moore, her daughter Tori, and I were sitting in a coffee shop, catching up on the weeks since my last visit to their home. Conversation turned quickly to Joanne's husband Alan, who had been diagnosed with early-onset dementia four years earlier. As usually happened when we talked, they recounted the ways in which life was changing as Alan's abilities shifted, a shift both wife and daughter read as decline. Today, however, I noted the way that their evaluations revolved around their home. Tori talked about how, as of late, her father had been startled to see her in the kitchen or coming down the hall, seemingly surprised that she would be in the house even though she had lived there for the past twenty-five years. She questioned whether her father still knew her. Joanne added that, when Alan woke in the night, he had started using a second bathroom down the hall from their bedroom, despite the fact they had a master bath connected to their room. "Do you think he doesn't know where to go?" Tori asked. Joanne affirmed the suspicion, "I think he probably just doesn't remember where the bathroom is, that we have one right there," and then went on, "I see him, sometimes, walking down the hall, and it's like he's trying to figure out where he is. It's like he's forgetting the house, like he can't remember much beyond what he sees, and so much is new each time he comes across it. And all the time, what he can remember is getting smaller." She shook her head and pursed her lips in a frown, "It's gotta be so hard."

The simple elegance of the description—the power of memory, habit, lived experience, and expectation to illuminate a space beyond the visual range—has stuck with me in the intervening months since we talked. It provokes several questions that sit at the heart of this chapter: What does it mean to "forget a house"? In what ways does that relate to forgetting a *home*? Or a

family? How is the ability to remember and navigate a space understood as relating to the power to envision and to enact a series of relationships? That is, in what ways is a project of figuring out *where* one is linked to a project of figuring out *who* one is? And what are the relationships between people and spaces that allow Joanne and Tori to connect the stories of not expecting to find your daughter in the kitchen and not knowing where the bathroom is? What are the ideologies of domesticity upon which they are drawing to understand their situation? And how do those ideologies structure both people's understandings and their responses to living with dementia?

In this chapter, I demonstrate that, for people diagnosed with dementia and their families, houses are deeply implicated in the experience of living with the condition, and in the way it is understood, translated, and tracked. Rather than containers in which the dramas and relationships of daily life with dementia are enacted, I argue that houses—as assemblages of spatial, temporal, and social relations—are central to the constitution of dementia as a condition that disintegrates families and persons. I do so by examining the stakes of “forgetting the house,” not only for Alan but also for Joanne and Tori, whose very articulation of this forgetting points to their own understandings of the relationships between a house, a home, and a family. While the house is a material structure filled with objects of domesticity, for middle-class families in the United States, “home” is the central place of family, marked not only by the kin relations of its inhabitants but also by their shared histories and daily interactions. Over time, houses become homes, producing and produced by families through the accumulation of memory and sociality. This thickening of a familiar web lends the home a sense of intelligibility and routine that makes it feel comfortable and supportive. Homes change constantly, yet despite continual fluctuations

of persons, materials, and situations, the home comes to be characterized by its stability, a stability which also is projected onto the family that occupies it. To forget a house, then, threatens to disrupt both material and social relations, to undo both home and family. As the layout and objects of the house become strange to Alan, so too, Joanne and Tori worry, do the memories, the histories, the lives and familial ties that wend through its rooms and hallways.

In the face of dementia's perceived threat to the home, families act to maintain continuity and stability, paradoxically by drawing upon its fluidity. I argue that, feeling unable to change the dementia, they instead make adjustments to the home in an effort to counter this estrangement. They alter rooms and routines, objects and orientations, in an effort to help the person with dementia "remember the house." In doing so, however, they often accentuate the very unease and dislocation they seek to resist as modifications become visible markers of the changes wrought both by dementia and their interventions. Families therefore work to reconcile the tension between staving off the "forgetting" and changing the house too much, reaching the breaking point of a home's ability to accommodate change and rupturing its stability permanently.

### **There's No Place Like Home: Ideologies of Home and Family in Middle-Class America**

Middle-class families in the United States ascribe to an ideology that powerfully links home and families, one within which the home acts as a site of stability and refuge that produces and protects well-adjusted nuclear families. This concern with a sense of constancy, and its grounding in the home, has historical roots in the mid-twentieth century, when many Americans were insecurely looking both backward over their shoulders at the recent decades of war and

depression and around them at the start of a new Cold War that threatened, at any moment, to turn hot (May 1988). An improved economic picture for many led to the rise of a considerable middle class in the 1950s, and bolstered by a newly found prosperity and strong government support, people began to invest their time and money in the development of a nuclear family centered within the suburban home (Coontz 1992). As historian Elaine Tyler May (1988) writes, “The legendary family of the 1950s...was the first wholehearted effort to create a home that would fulfill virtually all its members’ personal needs through energized and expressive personal life” (11). And while the apocryphal story of its timeless creation has been exposed as such, the persuasive power of the ideological connection between stable home and successful family is no less affective today (Coontz 1992).

Within this understanding of family, stability comprises safety, continuity, and predictability, and the center of this stability lies in the home. Home, as an ideal, is constructed not only from the house, as the material structure, but also from the relationships of those who inhabit it: individual’s relationships to each other, the house, and the world within which it exists. The imagined, idealized home is cast in contrast to a potentially dangerous outside world that is random and unknowable. While that which lies beyond its walls might be unpredictable, the home is characterized by routine and habit. People inhabit it, settling into grooves of daily activity, patterns of movement through which the house becomes known and comfortable. From getting ready in the morning to dinner routines, whether people embark upon ambitious “home improvement” projects or lazy movie-watching afternoons, the way that people interact not only with each other but with the materiality of their houses constitutes and transforms both person and house. Relationships form between material structures and the people that live within and

through them, and in this way, people become family, and houses become homes. Both become known, expected, *familiar*. Despite Thomas Wolfe's assertions to the contrary, the ideology of the stability assures you that you *can* come home again, and home will be exactly what you expect each time.

The appearance of stability papers over processes of familiarization and estrangement. Familiarization occurs as those characteristics that compose a feeling of stability become more deeply entrenched, through the way one makes coffee—whether using an automatic drip coffeemaker or a French press or a single-cup brewing machine; the process of getting the mail—when one retrieves it, from where (Is the mailbox on the side of the house? At the end of the drive? Near the door attendant's station?), and where it is then dropped; or how one gets ready for bed (Use the toilet, wash the hands and face, brush the teeth, turn down sheets, change into pajamas? Or maybe, pajamas first?). All of these routinized actions shape what it means to live in a home and are constitutive of a particular habitus, one that recursively reproduces not only the social distinctions evident beyond the home that were Bourdieu's primary interest, but also the micro-relations of domesticity. Estrangement, then, are processes that act in opposition to familiarization, that make the home seem somehow uncanny, as one can feel after minor disruptions, such as rearranging furniture or painting a room a markedly different color, or more serious ruptures, such as the death of a family member. Together, these processes are constant undercurrents through the home, giving shape to both it and families as people interact with houses and with each other.

### **“Too Bad We Aren’t Married”: Building Family and Home Through Memory**

Both in their late-50s, Elliott and Nancy Felder have been married longer than they ever lived apart. The couple met in 1974, when both were in their early 20s, and were married two years later. While they moved around in the first years of their marriage, as their family grew over the subsequent years, first with twin girls and then with a third daughter six years later, they finally settled in a ranch-style house in a Chicago suburb near extended family in the late 1980s. The two had just celebrated their thirtieth wedding anniversary when Elliott was diagnosed with early-onset dementia in 2006 at the age of 53. Two years later, early on in my research, his wife Nancy recounted the following to me during our first interview:

The other day he came upstairs...and he said, “You know, too bad we aren’t married.” And I said, “But we are.” He goes, “We are?” ...I was in the bedroom, I said, “Look at our wedding picture. That’s us.” “It is?” The next day he doesn’t remember saying that. Another time he said, “You know too bad you didn’t bring your clothes, you coulda stayed over night.” Or, “Do you wanna-” he says, and even during the day one time, we’re driving and he goes, “Well,” he says, “you wanna come to my house? You wanna come to my house?” So I know that things are progressing.

Under different circumstances her story could seem charming. It has the patina of a budding romance as Elliott flirts with her, asking her to stay the night. The idea that he would still seek a romantic relationship with his wife, still wishes they were married, is heartwarming. Yet the bittersweet nature of the narrative becomes apparent as Nancy talks about being in the bedroom they share as they have the conversation. Where they are—the fact that they are standing in their house, in their bedroom—is central to the poignancy of her story. She points to the picture on the wall to remind him, a portrait of the two of them from their wedding, and he cannot recognize them or their relationship that the photograph signifies. His affected memory is the critical missing link, and neither her own nor the photograph’s maintenance of their collective memory

seems enough to counterbalance Elliott's narrative. In her retelling, Elliott constructs a present in which they do not yet have a house together; in doing so, Nancy implies, he entirely "forgets the house," erasing the history of their home and, at the same time, their family.

The importance of memory in the projects of both home and family construction is clear in Nancy's narrative. These projects, as noted above, are endeavors of accumulation, an accumulation not only of material objects but also of such memories. The home, as a place both constituting and containing memories, has been productively explored over the past several years. As Bachelard writes, "thanks to the house, a great many of our memories are housed" (1994[1958]: 8). Scholars most frequently have discussed the ways that collective memory connects people and homes to generational and political pasts, as Joelle Bahloul (1996, 1999) elegantly illustrates in her work on *Dar-Refayil*, a house that binds several generations of Jewish and Muslim families in Algeria (see also Carsten 2004, 2007; Cole 2001). Yet, as Carsten writes, pointing to her own ethnographic evidence of photograph displays among adoptees, "The mixing of elements of old and new furnishings, heirlooms, and objects may thus express how houses capture the creative and regenerative aspects of memory work, rearranging the past, and also setting out a vista for the future" (2007: 18). As it weaves through homes, thickening the historical ties of their social and material relationships, memory not only connects to these deeper, broader pasts, it also works to constitute a present and give shape to a future (see also Marcoux 2001; Morton 2007). In this way, memories are seen as part of what makes homes and families intelligible, and that intelligibility is a key component of the perception of both as stable and continuous.

Yet the fragility of this project of accumulation—of the way houses are known to families

and family members are known to each other—and the necessity of that project’s continual reproduction, becomes apparent when a family member is diagnosed with dementia, a condition overwhelming understood as one that destroys memories and disrupts one’s ability to access them.

Moments that highlight the tenuousness of memory frequently are more mundane than those Nancy relates, the kinds of disruptions seemingly more subtle. Harold Lawton, for example, was having difficulties with his cabinets. The doors of the Lawton’s cabinets were wood, opaque, and Harold could not remember what was behind them—which cabinets held the plates and bowls, and which the pots and pans. Not knowing where the coffee cups are kept seems a minor issue. If Harold was thirsty, he could open doors until eventually he found the glasses revealed, take one, and fill with water at the sink. However, there were larger implications. One of his jobs in the family was to put away the dishes in the evening after they had been washed, and that was more challenging; often dishes would end up misplaced, plates with the pots or even in the pantry. The processes of putting them away and then locating them the next time they were needed were frustrating to both Harold and his wife Heidi. Not only did they mark a progression in his illness for the family, they also highlighted a shifting relation to both the house and the family. As Harold grew unable to put dishes away, his role in the maintenance of the home changed.

In an effort to resist these developments, the Lawtons took action on the house itself. Rather than attempting to alter Harold or act upon the changes associated with his dementia, they found the house a more suitable focus of intervention. If the house was no longer as intelligible to Harold, they would seek a way to make it so once again. They decided to take a Polaroid photograph of what was inside each cabinet and tape it to the front of its door. In doing so, they

were able to guide Harold's memory of where the dishes went, thereby keeping both routine and role intact. Both talked about their successful solution in the support group they attended the following month. And yet, the material change to the house (as with other memory devices people employ, such as calendars, whiteboards, or Post-It notes) was itself a constant reminder of the very need for intervention. The evidence of Harold's dementia was shifted from the misplaced pots and plates to a series of photographs taped to cabinet doors. This shift in the kind of visibility of dementia ordered and contained the illness for the Lawtons, bringing temporary stability to home and family and making both knowable once more. For this marker of change—change in the house in response to change in Harold—revealed the fragile stability and continuity the Lawtons sought to maintain and was a harbinger of an inevitable rupture in both family and home.

### **Short Nights and Long Days: The Temporality of Routine**

Harold Lawton's inability to remember what objects were kept behind which doors is a problem of routine as much as it is a problem of memory. Routines are a critical way of interacting with a house as a known entity. Their habitual nature, the unthinking familiarity with which they are enacted, marks oneself as belonging within the space as a regular member.<sup>1</sup> They reproduce and strengthen a relationship between house and person, and, through this work, serve to constitute the home. Within the context of dementia, however, routines can become more challenging. They are not "second nature," and the illusion of their supposed naturalization can no longer be taken for granted. Both for those diagnosed with dementia and for family

---

<sup>1</sup> Consider, for example, what it is like to "help" put away dishes at a friend's home after a meal.

caregivers, changes to routines can disrupt relationships within and with the home and thereby the family.

People with early-onset dementia frequently begin to feel shifts to their routines soon after their diagnosis, as characteristics that become marked as symptoms present. Prior to the appearance of symptoms, most people hold full-time employment, and oftentimes they are at the height of their career. The people with whom I worked who had professional careers outside the home, whether educators, businesspeople, lawyers, interior landscapers, or librarians, all were at a level of seniority marked by a high degree of both responsibility and stress. Days were tightly scheduled and structured, filled with meetings and already-overdue tasks to be completed. Many first noticed difficulties at their place of employment and soon were asked to leave or resigned. After, they found themselves at home, unsure of what to do across long stretches of unbroken day.

Steven Thomas, for example, was a high level executive with a telecommunications corporation, when he began experiencing problems at work. He found himself struggling to work through projects, staying at work to complete tasks that used to take him an afternoon. Professional relationships suffered, and soon it became clear, both to Steven and those who oversaw him, that he would not be able to continue. In February 2011, he left his job and shortly after was diagnosed with early-onset dementia. When I spoke with him later that summer, I asked him how he was doing, and he talked about his day, which was mostly spent walking the family's dog, running an occasional errand, reading, watching television, and going online. He was home alone much of the day. His wife Elaine was still working as a special education teacher, which allowed her freedom during the summer, certainly, but kept her busy during the

school year. Their two daughters happened to be living at home when we talked (one was home from college for the summer, while the other had moved home temporarily while she sought to start her nursing career), but both worked during the day. He was driving, but had fewer and fewer places to go. Elaine, who also was present as we talked, said that she found it hard to let him take things on, tasks like picking up groceries or returning library books, because he would inevitably return home having left some part of them undone. After the engagement, interest, and challenge he was used to in his career, he was finding it hard to fill his time. He was bored, as evidenced by, among other things, his constant status on Gmail chat: “I am up to nuttin” .

This boredom—a frequent topic of conversation among members in the support groups I attended—comprises intertwined temporal, relational, and spatial elements. The quality of the time that composes the day changes, as that which used to be highly structured and frequently changing (getting ready, morning commute, buying coffee at the corner shop, reading emails, checking schedule, heading into first meeting—just to tally, in a paraphrase of a former US Army marketing slogan, what happens before 9 in the morning) becomes more open, less ordered by these kinds of external demands. The rhythm of a day previously punctuated by peaks and valleys of action and engagement evens out. Yet, as is evidenced by the continued fast-paced schedule of both Elaine and the Thomas’s daughters, this rhythm does not change similarly for everyone in the household. While the contours of Steven’s daily life has changed, his is the only one that has assumed this new form, and indeed, he finds it out-of-sync with the shape others’ lives continue to have. Except for the daily life of his dog, as Steven told me, the other family member who remains, as he does, for the most part, at home.

More than just the person diagnosed, families living with dementia, as a whole, experience

the ways that changed routines unsettle the familiarity of the home. In the case of the Lawtons, their Polaroid solution allowed Harold to continue the activity of putting away the washed dishes, an activity and routine that helped to solidify his place both within the home and within the family. And while Heidi now saw the markers of Harold's dementia taped to their cabinets, the resolution was predominantly successful from her perspective: It helped Harold, maintained their relationship around this kitchen activity, and had little effect on her day-to-day interaction with the house. Such solutions, however, are not always so minimally intrusive for family members. Often, family members struggle to alter their schedules and routines in order to maintain home and family.

As discussed in chapter three, Kevin and Susan Smith felt the reverberations throughout the temporalities of their days. Susan talked about the shifts in routine. She told me about the household tasks that had been his and which had become hers. He still wanted to do them, she said, but could not anymore. Filling the water softener was one she related often, not only to me but also within her support group meetings. Water softeners require salt pellets to soften the water, and these pellets must be refilled as they wear away. The pellets come in forty-pound bags, which must be hoisted up over the side of the water softener and emptied into a small opening in its top. The last couple times that Kevin attempted to do so, the pellets missed the opening, scattering across the floor. So now, every four or so weeks, she would set the alarm for the middle of the night, two or three in the morning, to wake up, retrieve the forty-pound bag of salt from the back of her car where she left it so he would not feel bad about not being able to help, haul it downstairs, and empty it into the water softener.

In and of itself, the filling of the water softener is a minor task, as Susan would readily

admit. It was, however, a routine that indicated how much had changed, Kevin and his abilities, their relationship, the way they existed together within the home, both what they could not do and what they now had to do. In contrast to the Lawtons, who were able to change the house in a way that supported Harold's interaction with it, the Smiths seemed unable to do so. Instead, Kevin's routines became Susan's. It was not because they didn't attempt a similar solution where possible. For example, they labeled the garbage cans, distinguishing between recycling and trash, in an attempt to help Kevin maintain that routine. It did not seem to help, however, so was abandoned, and now Susan took out the garbage without enlisting Kevin's help. The water softener, however, was a different case. It was not an issue of Kevin not knowing where the water softener was or where the salt was supposed to go; rather, he was not able to manipulate the bag of salt.<sup>2</sup> The house, here, could not be sufficiently altered, so the routine was. And changes to the routine, as the Smiths were painfully aware, caused ripples across the fragile web of temporality, materiality, and sociality within their home.

### **Borderlands: The Marking of Public and Private Within and Without**

Within the context of dementia, refigured routines frequently occur in tandem with changes in the boundaries of a home. Home, in its conceptualization as a safe haven, as refuge, is constituted through the drawing of boundaries. Boundaries exist between the inside of the home and the outside world and between different spaces within the home, marking distinctions of public and private, familiarity and estranged. For families living with dementia, both often are

---

<sup>2</sup> As mentioned above and discussed further below, the changes associated with dementia extend beyond memory, despite cultural assumptions to the contrary that articulate dementia as only memory loss.

reconfigured.

Shifts such as that Steven was experiencing as he spent more days at home presage a decreasing porosity of the home's border for the person with dementia. The acceptable borders of homes are negotiated among family members and within communities in order to keep certain people out, to keep others in, and to allow still others to cross the border as they please. The enforcement (or not) of exclusion can be a means of marking intimacy, marking the boundary between the familiar and the strange. These borders can be marked by the locking (or not) of exterior doors or the evidence of alarm systems (stickers on doors or wires connecting windows to their frames) or something as simple as drawing the curtains over a window, keeping the outside world at bay. Within an encounter, they can be negotiated or even redrawn, as the party who was given entrance to the home tries to discern when the appropriate moment to leave is, so as not to overstay their welcome—not to invoke a shift from the familiarly included to the estranged excluded.

At the other end, borders also are enforced to keep some people within the home. They become visible through discussions over curfews or excursions like sleepovers, negotiations that also foreground the normative path of increasing independence for certain family members. As those familiar within a home engage more with the world beyond its borders, passage back and forth across them becomes recognized as an indication both of familiarity and of independence. If, then, part of the familiarity of a home has to do with one's perception of their own ability to enter and leave the home as they choose, the revocation of that choice, the thickening of those borders, can become a process of estrangement. As people with dementia no longer work and become increasingly restricted in their ability to transport themselves (whether by driving,

through public transportation, riding one's bike, or walking), as those who care for them have growing concerns about their safety outside the home, the borders of their homes become increasingly visible to them, not only marking a temporal boundary (separating them from that which they used to be able to do) but also a spatial one that they can no longer cross.

In some instances, families living with dementia can ease the transition that accompanies these thickening borders. Alex Reynolds, for example, has long been an avid bicyclist. At the time he was diagnosed with dementia in 2005, he frequently would embark for half-day or full-day treks on the weekend, heading out with a group of friends from his home in the southwest Chicago suburbs and following the trails and roads as far as they could carry him in a day's time. His home was a launching pad for biking adventure. Home was where he started, full of energy, and that to which he returned, ready to shower and recuperate; it was where he stored his bike and tuned it up. As he and his wife Bridget determined his dementia was getting worse, his balance was increasingly unsteady and they were less confident about his judgment. They decided that the biking excursions could not safely continue, so they began to look for alternatives. They settled on a trainer, a stand that turned Alex's bike into a stationary bike, allowing him to ride in place. The couple converted a room in the house to his "bike room," complete with his newly outfitted bike, a heart monitor so he could track his workout, and a television on which he could watch movies while he rode. Although he never talked about the switch as problematic, one can imagine that it was not easy, as several of the qualities that characterized what biking was—being outdoors, as part of a group, the challenges of navigating differentiated terrain—were stripped away. Yet, he was able to continue parts of the activity of biking, the pedaling itself, the exercise, the self-exertion, and Alex seemed satisfied with what

remained. When I first visited their home in 2011, this was the set-up that Alex used; he took me upstairs and showed me the bike, even getting up on it and demonstrating. His enthusiasm for riding was clear, as he told me he would go for two-hour rides on weekday mornings while Bridget was at work.

Biking was moved indoors, a move that marked a shifting boundary between inside and outside of the home. It involved heading upstairs to a room on the second floor rather than to the garage and beyond. The home was where the activity occurred rather than simply an area of preparation and recovery. The boundary between inside and outside had thickened, but in a more complicated way than the shrinking of the world that Steven describes. Biking indoors separated Alex from the outside, protecting him from the potential dangers of streets and trails, where he might have an accident or become lost. Yet by creating a bike room, the Reynolds also reinscribed a relationship between indoors and outdoors inside the home. Through the activity of biking, the boundary seems slightly thinned, less prohibitive. And the flexibility of the Reynolds' home and relationship could accommodate this reinscription.

### **Hazardous Materiality: “Safety” Within a Home**

When the home is explicitly mentioned in the vast array of literature for family caregivers—guidebooks and self help materials—it frequently appears as house. That is, its materiality is what matters, as an architecture filled with objects. House, as one facet of home, comprises the structure, the materials used to construct it, its shape, and the flows and pathways it engenders, as well as the material objects and possessions that fill it—the furniture of living rooms, dining rooms, and bedrooms, the items that compose the kitchen, the knickknacks and art and heirlooms

that adorn shelves and walls. Through this materiality, “the house comes to occupy us as we come to occupy it” (Miller, 2001: 11). For families living with dementia, the fluidity of this process of co-constitutive “occupation” becomes markedly clear as people’s relationships to the materiality shift.

The most explicit discussions of home-as-house are framed in terms of “safety.” Indeed, while a key component of the boundary drawing that takes place in homes attempts to preserve a sense of security against external dangers, in the context of dementia, the materiality of the house as a protective barrier may itself become problematic. Is the person with dementia or others around her in danger of harm? Discussions of safety are discussions of the predictability of the material world and the way one interacts with it. The house therefore becomes threatening when it is unpredictable, when the person interacting with it is unpredictable because of the dementia. For example, the house is discussed as an area of potential hazard in a chapter entitled “Problems in Daily Care” in *The 36-Hour Day* (often considered the seminal “family guide to caring” for people with dementia). “A neat house is safer than a cluttered one,” the section opens (1999/1981: 61). Potential dangers, detailed across the course of three pages, can come in the form of the objects which fill a house, calling out the hazards of what Jeanne Arnold (2013) has recently called middle-class Americans’ preoccupation with “mountains of things.” The guide warns of irons, power tools, lawn mowers, knives, hair dryers, sewing machines, cars, medications, hot water, rugs, furniture with sharp corners, rocking chairs, glass items and other breakables, liquids one might swallow (including cleaning supplies, insecticides, gasoline, paint, solvents) and other things one might eat (the list includes paint chips, buttons, and pins). In addition, the structure of the house itself is suspect: stairs, tiled floors, rooms people can lock

themselves inside, and windows or balconies are all identified as potential threats. Kitchens and bathrooms, the guidebook's authors warn, are particularly dangerous, with fire-hazard stoves and slippery bathtubs.

More than just the purview of care manuals, safety within the house was also a concern of both the families and care professionals with whom I worked. Craig often spoke of his primary caregiving role as one of "keeping [his wife] Lisa safe." Indeed, the instigating factor when they decided she should move to a long-term care facility was a fall in the shower; she had fallen while bathing, injuring both herself and her part-time professional caregiver. When Craig talks about it now, he says that that fall was a warning, that next time would be worse, and he couldn't live with that. Shawna related a story during a support group meeting about Jonathon heating up his coffee in the microwave for several minutes, long enough that the coffee exploded, cracking the cup and spattering the inside of the microwave with hot, caffeinated liquid. While her recounting was humorous to those in the room, certainly, it also had a hint of foreboding, a list of 'what ifs' that turned the microwave perilous. Shortly thereafter, she bought a single-cup coffee machine for Jonathon to use. The social worker at the Alzheimer's Disease Center where I conducted fieldwork often talked about the importance of contrasting colors—for walls and floors, or stairs—to ensure that a person with dementia recognizes the two surfaces as distinct and avoids, for example, running into a wall they cannot see. At an annual examination visit to the memory clinic, one wife discussed her husband's recent falls; twice, he had fallen down stairs, once while they were out and once off the front porch of their house. The nurse practitioner at the clinic that morning suggested that they might try putting reflective tape on the edge of each step, so that he notices the difference in height from one to the next.

Homes as houses—both that which fills them and their very architecture—become *different* for people with dementia. They become strange as the nature of one’s relationship with their materiality changes. Buttons and glass cleaner become edible, steps become opportunities to fall, and walls become floors. The material of one’s house increasingly elicits a range of alternative uses and unpredictable outcomes. The opening, fictionalized vignette of *36-Hour Day* illustrates the way this shift is conceptualized:

For Mary the bath became an experience of terror. The tub was a mystery. From day to day she could not remember how to manage the water: sometimes it all ran away; sometimes it kept rising and rising, and she could not stop it. The bath involved remembering so many things. It meant remembering how to undress, how to find the bathroom, how to wash. Mary’s fingers had forgotten how to unzip zippers; her feet had forgotten how to step into the tub. There were so many things for an injured mind to think about that panic overwhelmed her (1999: 3).

As it is written, Mary’s bath becomes foreign. The authors write that the “bath involve[s] remembering so many things,” and this is true in two senses. First, the material of the bath—the hard-to-control flow of the water, the distinction between hot and cold knobs, the slipperiness of the porcelain, awkwardness of the curtain. She is uncertain how it functions, what the water does and how to control it. Its very materiality becomes unreliable. Along with the bath itself, the *activity* of bathing is called into question. What is Mary supposed to do in the tub? And what are the activities that lead up to it, that make bathing—and, importantly, bathing a particular way—possible?

The difference of the house, the shifts in activities that occur within, also reflect a change that people themselves are undergoing. The changes in Alex’s bicycling habits were due to other changes he was undergoing, namely increasing physical instability and memory loss. The changes in his relationship to the house, then, marked not only changes in his activities but also

shifts in Alex. In the example of Mary, her “injured mind” becomes overwhelmed at the thought of interacting with the bathtub. The person with dementia must be protected from not only the house, as they can be misinterpreted, misused, misnavigated, but also from themselves and the effects of dementia. Or, consider the following suggestion: “Lower the temperature on your water heater so that water is not hot enough to scald the person who accidentally turns it on. People with dementing illnesses can lose the ability to realize that hot water is too hot and they can burn themselves badly. If hot water pipes are exposed, cover them with insulation” (Mace and Rabins 1999: 61). The water heater and pipes, the water that flows from them, are sources of danger, but so is the person, who may “lose the ability to realize,” a loss that is the result of their “dementing illness.” In yet another caregiving guide, the section entitled “Keeping the Person with AD [Alzheimer’s Disease] Safe” is structured, in part, around the person’s senses—dangers arise because they might no longer correctly interpret what they see, hear, smell, taste, and touch (2009: 40-4). In each possible mishap, house, person, and illness converge.

As the material nature of the house becomes different to the person with dementia, so too does it change for other family members. Family members are asked to be vigilant to these previously unforeseen dangers, to mark the edges of steps and paint walls, to lock up medications and poisonous chemicals. Through clinic appointments and support group meetings, social workers, nurses, and other professionals, care manuals, and other families all “train” family members to see the threat potential inherent in the materiality of their houses.<sup>3</sup> They learn

---

<sup>3</sup> ‘Training’ family members as caregivers, especially through support groups, has been discussed elsewhere in the literature. Gubrium (1986) writes about this training as a process of teaching them how to understand the changes of their family member as dementia, and how to emotionally experience and articulate what their family is going through. Blum (1992) has written on the ways that family members come to accept deceiving their loved ones as a

that they should be proactive in their assessment of the house, and like Craig and Shawna, they need to react when family members with dementia interact with the house in ways that are seen as incorrect or inappropriate. And that process of assessment involves seeing differently, trying to see stoves, showers, and steps as a person with dementia might, to imagine how they might be used. For both person with dementia and their families, the house becomes seen as unpredictable, and people become estranged from the home.

### **The Limits of Flexibility within Home and Family**

*“August 1, 2009 — a kind of new phase of the illness in which Holly picks up items randomly, from the floor, or a desk, or something, and tries to figure out where it is supposed to go, even though it was already in the right place. Her instincts for organizing things is coming in direct conflict with keeping things in proper order.”*

Tom Roberts wrote this journal entry about his wife Holly and what he saw as her attempts to organize their home in the electronic document entitled “Alzheimer’s journey” a little over five years after she was diagnosed with early-onset dementia. I had met Tom and Holly in late March 2009 at a support group, a few months before he typed these words, but the couple often was quiet. Both tall and thin, their presence was as slender as their frames. When he gave me the document in February 2011 as I began working with them, then, I was struck by the words, having just finished an interview with the couple during which Holly spent much of her time doing exactly what Tom seemed to be describing, trying to figure out where things belonged. And in contrast to what I thought of as her typically quiet demeanor, Holly was visibly and vocally unsettled as she went about this work, trying to settle, I imagined, both herself and her

---

necessary form of behavioral control.

home.

I arrived at their house late one Wednesday afternoon, a large brick home originally built in the early 20th century, and Tom answered the door, welcoming me in and warning me that Holly was upset. “It’s one of the complications,” he said of her distress, “If you want to wait, I’ll be just a couple minutes.” He left me in the living room, heading back to where I could hear her crying.

While I waited, I wandered about the living room, taking in its ethos, a lived-in sensibility, I thought, that seemed most plainly evident in a blend of well worn furniture and chaotic messiness. I paused to read a framed print of the Robert Louis Stevenson poem, “Lamplight.” “My tea is nearly ready and the sun has left the sky;” its images captured well an antiquated slice of life that seemed just at home with the Roberts.

I was brought back out of my ethnographic reverie as Tom came through the dining room with Holly. Immediately, the air of the room electrified, thick with their tension, their discomfort in the moment, in their own space. He led her across the room, slow and careful steps as she cried softly. “Why don’t you come in the kitchen?” he asked, “You can sit in there.” “I don’t want to,” she replied, an infrequent occurrence from what I understood. “Do you want to sit in the living room? You can do that if you want,” he switched direction and guided her out to a couch that sat below a drapery-covered picture window. He helped her settle on the couch, turned on the light that sat upon a nearby endtable, and handed her a doll, explaining to me that he found it brought her comfort. But as we began the interview, Holly set the doll to her side and went off toward another part of the house where I could hear water begin to run.

After a time, she returned to the dining room, sniffing and crying again. The water was still

on in the other room, and Tom paused our conversation momentarily to turn it off, quickly returning and apologizing once again. As we talked, Holly moved about the dining and living room, picking up papers and envelopes, transferring them to other stacks, bringing them to the table. Sometimes, she would show them to me, looking at me with an intensely furrowed brow, almost accusingly, as if asking me to do something with them, to right some disorder within the house.

For Holly, the house was, in some way, a source of distress. Whether because, as Tom posited, she had an instinct for order that she was not able to actualize that afternoon, or because her movements and organizational efforts were an attempt to communicate something that went unrecognized, she had become estranged from the home and could no longer act effectively on it or its inhabitants. Holly's efforts to re-order the house also created distress and disorder for Tom, he told me in subsequent conversations. In the seven years between her diagnosis and when I first met them, the Roberts had undergone a number of changes that affected the contours of familiarity within their home. The activities that Holly found engaging shifted over time, from reading and doing puzzles to the nervous project of organization I had witnessed. Tom found that showering was less objectionable if they did it together. Going to the bathroom became a constant struggle, as Holly frequently resisted, refusing to sit down on the toilet. Tom now did all the cooking, an endeavor he described as "functional," and much of the cleaning that was formerly split along what he called "more traditional gender roles." After she left the home one afternoon while he worked in the home office he'd begun keeping after her diagnosis, Tom installed a lock on the doors to the outside that could only be opened with a key he kept. They began having people in the house to be with Holly when he was not able to do so, first their

daughters or friends, and later people that they paid, and finally in August 2010, a woman moved into their basement to act as a live-in caregiver. Over this time, their relationship to their home changed, with all that entailed. The structure itself was altered—locks on doors, a basement converted to an apartment—as well as people’s relationship to those material items that filled it—as one person could no longer work in a kitchen, another began to; a bathroom became a less private space; papers, formerly properly piled, became distressing and unruly. Routines changed, as morning preparations became something completed together, work became something done inside, then outside the home, days were spent at day programs or with others, but certainly not alone. Relationships changed, as people were welcomed into the house for a new purpose

Holly had attended a day program located near their home (the one to which she’d been returning that day I first went to their home) since the fall of 2007. Based on his journal and our conversations, Holly seemed to find the day program at least acceptable. In early 2010, he describes her experience, partially excerpted here:

March 5, they had a staffing [*sic*] for [Holly] at [the day program], which I attended. They were quite upbeat. . . . They had mostly positive things to say. She seems to socialize well, and show preferences with regard to what activities that she wishes to participate in. There are certain friends she seems to have. She dances—something I haven’t seen. Maybe I need to go there too and learn to dance. . . . I told them that is crying here at home. This is not occurring at [the day program]. I guess they keep them too busy.

The description is telling here insofar as Tom recognized and distinguished between what she did at home and what she did at the center; he pointed specifically to a difference in her behavior in each place. She was “crying here at home,” which was “not occurring at [the day program].”

This distinction of place is most notable when he writes of her dancing and the potential benefit of his joining her. He might “need to go there too and learn to dance,” he wrote. While I read this

as likely a moment of lighthearted jest (a rare one for Tom, whose pragmatic sensibility is one of his most clearly rendered qualities), the sincerity of his intent to actually go to the day center and dance does not affect the fact that Tom did not write, “We could dance together at home, too.” As the one increasingly tasked with the interpretation of situations such as these, Tom seemed to attribute her improved affect and reaction to her experiences as, at least in part, shaped by the space she occupied and the possibilities of that space to be comforting for Holly in ways that the home no longer was.

\*\*\*

In late April 2011, Tom moved Holly to a long-term care facility ten blocks from their home of thirty-five years. From one perspective, the decision was a quick one, made and executed over the course of a weekend. As I’ve detailed here, however, from another vantage point, it had been building for some time, the result of a series of estranging shifts—of altered routines, of reinscribed boundaries, of increasingly unpredictable materiality—that had affected not only their relationship to the space they shared, but to each other, leaving them both uncomfortable in their home and with each other.

Initially, Tom avoided going as much as possible. He did not like seeing her there, questioned whether she was receiving the level of care and attention that he could provide at home, and found himself unsure how to act, what to do. When we would go together, his visits were short and perfunctory. Over time, however, their activities changed, and he talked about enjoying their time together. He did not go every day, as some others did, but he went a few times a week. He would help her eat, if it were around dinner time, and then they most often would spend time in her room, quietly holding hands or just sitting close to each other. She was

content to do so, as well. When I last talked to him about it, he described it as a resumption of their relationship as husband and wife. We were seated in his living room at the time, and I noted the difference in the way Tom occupied the space of their house: He seemed comfortable in a way he never had when Holly lived there.

In one reading of the Roberts's narrative, neither the home nor the family could any accommodate the changes that were asked of them. The limits of their flexibility had been reached, leaving both, it would seem, broken as Holly was forced to physically leave the house in what might appear to be a final drawn boundary of exclusion. Yet over the months I visited Tom after Holly had been moved to the nursing home, the way he talked about the place, his and Holly's relationship to it and each other, as well as how they acted together within it, led me to reconsider how I viewed the potential flexibility of their home and family. The Roberts's example illustrates that "home," insofar as it means the continuity and stability of family, can be uncoupled from the materiality of the house. Neither Tom nor Holly could maintain the relationships of family within the physical space of their house. Yet, while certainly boundaries had been redrawn, and without doubt the tenuous nature of home and family were stretched to their limit, in a way, it seemed as though Tom and Holly had found a bit more give as they spread family across the spaces of their home and the nursing home. They found a little more support within their family to continue to accommodate the maintenance of their spousal relationship.

### **Finding Family in the Garden**

While the Roberts sought to maintain some semblance of family and home by separating them from the house almost completely, accommodation does not always require such radical

restructuring, even when family are forced to move beyond the walls of the house. Sometimes, a process of re-familiarization, of reproducing the stability and continuity of home, of “remembering the house” occurs just outside.

It is not an overstatement to say that Alan Moore loves his garden. “Oh, yeah,” he tells me, as we both sit upon the deck, looking out across the landscape, “Yeah. I mean, I could be here all day.” A former interior landscaper, he spent most of his career designing, building, and tending to the large scale gardens that are popular in the lobbies of office buildings, hotels, and malls. Over the years, until recently, Alan has been the guiding force behind the shape that the garden has taken. After he lost his job—a loss that retrospectively the Moores attribute to the early confusion caused by dementia—he spent much of his time working out here. In many ways, his wife Joanne has told me on several occasions, the garden was always his project, one they have always all been able to enjoy.

Over the time I have been working with the Moores, Joanne has talked about the challenges of their garden, especially in the last year. Alan has not been able to do the same work that he always did. The wheel on the wheelbarrow needed to be replaced, and he couldn’t make the repair. Joanne and their daughter Tori ended up fixing it. Early in the spring, the soil needed to be tilled, and Alan could not use the Roto-tiller this year, so their son, who lives a three-hour drive south, came in one weekend to do it. They put in a winding stone path among the vegetable portion of the garden to make it easier to maintain. There was a time, to hear Joanne tell it, when Alan would have done that work himself. This year, they hired people to come in and do it. In the past few years, they also have hired people to mow the lawn.

As we sat on the deck a couple months ago, I asked Joanne why she continued the garden,

given the amount of work it requires. Amid talking about how it gave her something to do and the ways in which she enjoyed it, she discussed Alan:

It was Alan's thing. Really. You know, Kind of his vision of things that he liked. He was always into gardening from his grandpa. [...]That's why we live here. And now it's something that Alan enjoys just looking out at the yard. He always says, "Oh you did such a great job this year on the garden!" And it used to be his thing. So...sort of like taking over for him. [...]It's something he started, and I'm trying to keep it up. Because it's, you know, Alan.

The day before, all of us were working outside, along with Joanne and Tori. The women focused primarily on clearing and planting, Tori moving her delicate, tiny sunflower stems, cupped in half eggshells filled with a few spoonfuls of dirt, from where she'd started them as seeds to an outdoor patch, and Joanne digging out remains from the previous season. Alan and I took piles of torn, dug up, and discarded greenery to the compost. We cleaned the birdfeeders, and I watched as Alan carefully scrubbed the bowl, stone inside of each, helping him set it back on the stand when his perceptual changes made it difficult for him to center it. At one point, when he asked how he could help, Joanne asked him to fill the birdfeeders. As he moved from feeder to feeder across the yard, I watched as Joanne kept him on task, reminding him when he would set down the seed-filled, green plastic watering can and head off to something else he saw needed doing.

Across the garden, a dense web of family and home was being cultivated. The "house," forgotten inside was being remade out among the rose bushes and patches of weeds. With the garden as the focus, the binary of "family caregiver" and "person with dementia" was momentarily disrupted. For a few hours, sometimes for a conversation or the amount of time it takes sandhill cranes to pass overhead or orioles to land to dip into a glass dish of grape jelly, the

overdetermined understandings of dementia, of what it was doing not only to Alan's body but to the Moores' home and family, were allowed to recede. For that time, Alan, Joanne, and Tori reproduced home and family in the space of the garden, and that work of cultivating the family was foregrounded. Joanne gave Alan a next project when he asked; later, when he'd headed back inside to clean up, she would go around to the feeders and check them, finishing filling them or even changing the type of seed, if necessary. Tori made sure we were all kept fed and watered. Alan cleaned and refilled the birdbaths with a careful thoroughness. When he didn't know how best to help, he asked Joanne. Even I found myself in the midst of it, centering birdbath bowls, helping weed and plant. And, of course, the garden, the birds, the chipmunks, breeze, and sun acted upon the four of us, as well.

## **Conclusion**

If estrangement is a process that threatens the constitution of the familiar, that disrupts the building of the home, what does that process look like? What are its elements? Or, better, where does it become evident? As discussed above, a home is constantly built, and the constitution of it as more or less familiar changes across the course of its and its inhabitants lives. In a middle-class, Midwestern home, people may marry, have children, divorce, retire, and die; they may repaint, refurnish, add on to, gut rehab, and move to or from. Children might come rushing home, seeking comfort, from a bad day at school or a sleepover, while teenagers might avoid the home as much as possible. Someone might move back to the house, when they have an unexpected break in employment or as the family decides they are too sick or frail to live alone any longer. Upon retirement, spouses discuss having to "relearn" their house, how to be with

each other in the same space for much longer periods of time. It is important to stress that these processes of familiarization and estrangement are, in many ways, common to everyday life and the building of all homes. The context of dementia, then, does not act as a complete break from the flow of daily life as much as it acts as exemplar of the work necessary at the limits of estrangement. Rather, it illustrates the ways that the construction of familiarity in the US is a process of papering over discontinuities to highlight coherence. Attending to the changes evidenced by a person diagnosed with dementia provides ethnographic evidence that this process is continually articulated through a person's relationships with the materiality of her home, its space and the things that fill that space; its temporality and the routines and routes established through and around it; and those people who occupy it.

## Conclusion<sup>1</sup>

In late spring of 2012, my partner and I were having dinner with two other couples. About halfway through the meal, we were talking about the Chicago Architecture Foundation's River Cruise, as they had just bought tickets to go in the coming weeks. My partner, a CAF enthusiast, asked if they had gone before. Joanne answered that it had been a long time, and her husband Alan followed up, saying that the last time they had gone was when they had taken the photograph that was hanging in their basement. Joanne sharply said, "What are you talking about? You're talking about the picture of my dad? That's not from the tour."

"No," he replied, starting to explain.

"Oh, it *reminded* you of the picture?"

"Yes," he nodded.

"Okay, sure," she said. A beat later, she corrected him about the picture's location—at the top of the stairs, not in the basement. And two minutes after, our food had arrived; we had already moved onto another topic of conversation.

Yet, on the ride home, my partner and I discussed that short exchange for most of the hour-plus trip back to Chicago from the suburbs. We were both discomfited as Joanne snapped at Alan and then chided him about where the picture hung. More so because Alan was living with early-onset AD. In my fieldnotes, I wrote, "In the end, who cares [where the picture was or whether it was from the tour or another time]? What was gained in that moment? She could actually have used the moment to tell the story of the picture to [my partner] because it's a cool story."

---

<sup>1</sup> A slightly revised version of this conclusion appears in the online journal *Medicine Anthropology Theory* (2015).

And it has stayed with me through my dissertation writing process, although not entirely for the reasons I jotted in my notes that evening. As I thought about the conversation, talked it over with friends and colleagues, wrote iterations of it in notes and memos and paper drafts, what I kept returning to was my own reaction. My discomfort seemed to stem from three assessments: 1) Joanne was short with Alan; 2) She was short with him because he was remembering incorrectly a fact about their shared lives; and 3) Alan has a condition that compromises his ability to remember exactly those kinds of things.

I became increasingly uncomfortable with the fact of my own discomfort. It seemed an appropriate reaction within the paradigm of the “person-centered” care model—or at least in the way that the paradigm is increasingly taken up as an ethical approach to both professional and family caregiving in US and Western European contexts. British social psychologist Thomas Kitwood, who is credited for most fully articulating the ideals of person-centered care within the context of dementia, stressed the importance of the model’s focus on relationality (1997). For Kitwood, the “malignant social psychology” that results in a diminished personhood of the person with dementia comes from the lack of an understanding that personhood is inherently social and interdependent (1993). Unfortunately, as others have critiqued (e.g., Nolan 2004), the dominance of a consumer-based healthcare system predicated on personal autonomy and choice has rendered “person-centered” as “individual-centered” (see also Mol 2008). This reworking strips the model of the tenets which actually sit at its foundation: a focus on relationality, and a recognition of personal and social histories and interdependencies.

The intensity of my discomfort stemmed from the disjuncture between the model and the, as Paul Brodwin (2013) has termed them, “everyday ethics” of person-centered care as it is

employed in real-life care situations. My reaction indicated a reading of Alan and Joanne only as a person with AD and a family caregiver, and it seemed to privilege the support of and attention to Alan's personhood (as person with AD). Failing to fully historicize them as two people who had a forty-year relationship, I reduced their relationship to a synchronic slice, constantly reproduced ahistorically in these roles of caregiver and person with AD. The tenor of their exchanges before Alan's diagnosis, what they looked like and how that worked for them, fell to the wayside. The way they joked, the moments of quiet care, anger, sadness, the texture of their lives outside that conversation were left unaccounted for. Even that day's events, which included Alan's day program administrators calling Joanne and insisting that she come to pick him up before she was able to finish the household tasks and errands on that day's docket, didn't figure in my reaction to the moment. My reaction also neglected to consider the full complexity of Joanne as a person, in addition to both a spouse and a caregiver. As I initially saw her, Joanne *couldn't* be angry because she was supposed to be caregiving in that moment. Often in person-centered care, a more complete personhood of the family caregiver is invoked—in discussions about ensuring time for yourself, protecting an identity beyond “caregiver,” and allowing yourself to feel angry or guilty or sad (e.g., Boss 2011, Mace and Rabins 2006). Yet, the moral weight of caregiving and imbalanced import of people's personhoods often overshadows these voices (Nowhere is this more evident than in the admonishment to “care for yourself so you can care for your loved one.”<sup>2</sup>) Within the refigured understanding of person-centered care, there was

---

<sup>2</sup> “The well-being of the person with dementia depends directly on your well-being. *It is essential that you find ways to care for yourself so that you will not exhaust your own emotional and physical resources*” (Mace and Rabins 2006:226, emphasis in original).

no place for these other considerations: All that could matter was the way Joanne diminished Alan's personhood as she called out his changing memory.

Such disenfranchisement, I hasten to stress, *is* important. The concatenation of those moments is precisely what engenders the social death of dementia, and they should elicit discomfort as we witness them. But they should also be examined within a fuller historical and social context, taking into account the ways that overdetermined narratives of Alzheimer's disease and family caregiving in the US shape the moral imagination of families living with AD.

As I contemplated this through multiple oral and written reworkings, I realized that it aligned with another concern that had continued to prod at the back of my mind throughout my research and writing: anthropology's engagement of people living with dementia and their family caregivers. Starting from Jaber Gubrium's work in the mid-1980s, medical anthropologists and sociologists have levied a steady critique against the medicalization of senility, tracing the ways that it undermines the personhood of those living with dementia (e.g., Cohen 1998, Gubrium 1986, Leibing and Cohen 2006, Lyman 1989). The scholarship of this "personhood turn" (Cohen 2006, Leibing 2006) forces a reorientation; as Janelle Taylor so elegantly puts it, "When everyone keeps asking me [about her mother, who is living with dementia] 'Does she recognize you?' I believe the question really is—or should be—"Do you, do we, recognize *her*? Do we *grant her recognition*?" (2008:315). This is crucial work, I believe. However, across my dissertating process, I have also come to believe that work which focuses on the personhood of the person with dementia can, with slippery ease, occlude the personhood of those who interact with her—clinicians, care professionals, family members, and friends. In doing so, it threatens to

reproduce the very individualizing trend—seen in person-centered care—that anthropology seeks to resist and critique.

As I have worked through the moment between Joanne and Alan that night in my analysis and writing, its malleability has led me in multiple directions, from histories of Alzheimer’s disease and family caregiving through considerations of the materiality of the home to ideologies of the nuclear family, activity, and intimacy. Across this, my hope, of course, is that a field of ethnographic vision that includes both the person with dementia and those with whom she interacts will provide a more nuanced portrait of life with dementia, one that can account for Joanne and Alan’s myriad complexities beyond their caregiver and person with dementia roles, one with room enough for the social life of all persons involved.

## Bibliography

- AARP, and National Caregiving Alliance. "Caregiving in the US, 2015." 2016, <http://www.caregiving.org/caregiving2015/>, accessed April 10, 2016.
- Abel, Emily K. *Hearts of Wisdom: American Women Caring for Kin, 1850-1940*. Cambridge, MA: Harvard University Press, 2000.
- Adams, Vincanne, Michelle Murphy, and Adele E Clarke. "Anticipation: Technoscience, Life, Affect, Temporality." *Subjectivity* 28, no. 1 (2009): 246-65.
- Arno, Peter S., Carol Levine, and Margaret M. Memmott. "The Economic Value of Informal Caregiving." *Health Affairs* 18, no. 2 (March 1, 1999): 182-88.
- Alzheimer's Association. "Changing the Trajectory of Alzheimer's Disease: A National Imperative." Chicago, IL: Alzheimer's Association, 2010.
- Alzheimer's Association. "Generation Alzheimer's: The Defining Disease of the Baby Boomers." Chicago, IL, 2011.
- Alzheimer's Association. "2016 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 12, no. 4 (2016): 459-509.
- Alzheimer's Study Group. "A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group." Washington, DC: Alzheimer's Study Group, 2009, Electronic Document, [http://www.alz.org/news\\_and\\_events\\_16243.asp](http://www.alz.org/news_and_events_16243.asp), accessed April 3, 2016.
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association, 2000.
- Andersen, Hanne. "Epistemic Dependence in Contemporary Science: Practices and Malpractices." In *Science after the Practice Turn in the Philosophy, History, and Social Studies of Science*, edited by Lena Soler, Sjoerd Zwart, Michael Lynch and Vincent Israel-Jost. New York: Routledge, 2014.
- Armstrong, David. "Chronic Illness: A Revisionist Account." *Sociology of health & illness* 36, no. 1 (2014): 15-27.
- Arnold, Jeanne. 2013. Mountains of Things. In *Fast-Forward Family: Home, Work, and Relationships in Middle-Class America*. E. Ochs and T. Kremer-Sadlik, eds. Pp. 67-93.
- Bachelard, Gaston. 1994[1958]. *The poetics of space*. M. Jolas, transl. Boston: Beacon Press.

- Bahloul, Joelle. 1996. *The architecture of memory: a Jewish-Muslim household in colonial Algeria, 1937-1962*. C. du Peloux Ménagé, transl. Cambridge, New York: Cambridge University Press.
- Bahloul, Joelle. 1999. The memory house: time and place in Jewish immigrant culture in France. In *House life: space, place and family in Europe*. D. Birdwell-Pheasant and D. Lawrence-Zuniga, eds. Pp. 239-249. Oxford: Berg.
- Baldwin, Clive, and Andrea Capstick, eds. *Tom Kitwood on Dementia: A Reader and Critical Commentary*. New York, NY: McGraw-Hill Companies, Incorporated, 2007.
- Ballenger, Jesse F. *Self, Senility, and Alzheimer's Disease in Modern America: A History*. Baltimore, MD: Johns Hopkins University Press, 2006.
- Basting, Anne Davis. *Forget Memory: Creating Better Lives for People with Dementia*. Baltimore, MD: Johns Hopkins University Press, 2009.
- Bayley, John. *Elegy for Iris*. New York, NY: Picador, 1999.
- Beach, Thomas G. "The History of Alzheimer's Disease: Three Debates." *Journal of the history of medicine and allied sciences* 42, no. 3 (1987): 327-49.
- Becker, Gay. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley, CA: University of California Press, 1997.
- Benjamin, AE. "An Historical Perspective on Home Care Policy." *The Milbank Quarterly* (1993): 129-66.
- Berg, Marc, and Annemarie Mol. *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*. Durham, NC: Duke University Press, 1998.
- Berlant, Lauren. *Intimacy*. Chicago, IL: University of Chicago Press, 2000.
- Binstock, Robert H., Stephen G. Post, and Peter J. Whitehouse. *Dementia and Aging: Ethics, Values, and Policy Choices*. Baltimore, MD: Johns Hopkins University Press, 1992.
- Blum, Nancy Sue. "Becoming a Caregiver: Processes in the Career of Caring for a Family Member with Alzheimer's Disease." University of California, Los Angeles, 1992 (dissertation).
- Bookman, Ann, and Mona Harrington. "Family Caregivers: A Shadow Workforce in the Geriatric Health Care System?." *Journal of Health Politics, Policy and Law* 32, no. 6 (December 1, 2007 2007): 1005-41.
- Boris, Eileen, and Rhacel Salazar Parreñas, eds. *Intimate Labors: Cultures, Technologies, and*

- the Politics of Care*. Stanford, CA: Stanford University Press, 2010.
- Boss, Pauline. *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief*. San Francisco, CA: Jossey-Bass, 2011.
- Braithwaite, Valerie. "Caregiving Burden: Making the Concept Scientifically Useful and Policy Relevant." *Research on Aging* 14, no. 1 (March 1, 1992 1992): 3-27.
- Buch, Elana D. "Making Care Work: Sustaining Personhood and Reproducing Inequality in Home Care of Older Adults in Chicago, IL." University of Michigan, 2010 (dissertation).
- Buch, Elana D. "Senses of Care: Embodying Inequality and Sustaining Personhood in the Home Care of Older Adults in Chicago." *American ethnologist* 40, no. 4 (2013): 637-50.
- Buchbinder, Mara. *All in Your Head: Making Sense of Pediatric Pain*. Berkeley, CA: University of California Press, 2015.
- Buhler-Wilkerson, Karen. *No Place Like Home: A History of Nursing and Home Care in the United States*. Baltimore, MD: Johns Hopkins University Press, 2003.
- Bucks, RS, DL Ashworth, GK Wilcock, and K Siegfried. "Assessment of Activities of Daily Living in Dementia: Development of the Bristol Activities of Daily Living Scale." *Age and ageing* 25, no. 2 (1996): 113-20.
- Carr, E Summerson. "Enactments of Expertise." *Annual Review of Anthropology* 39 (2010): 17-32.
- Carsten, Janet, ed. *Cultures of Relatedness: New Approaches to the Study of Kinship*. Cambridge: Cambridge University Press, 2000.
- Carsten, Janet. *After Kinship*. Cambridge: Cambridge University Press, 2004.
- Carsten, Janet, ed. 2007. *Ghosts of Memory: Essays on Remembrance and Relatedness*. Malden, MA: Blackwell Publishing.
- Charmaz, Kathy. *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press, 1991.
- Chaufan, Claudia, Brooke Hollister, Jennifer Nazareno, and Patrick Fox. "Medical Ideology as a Double-Edged Sword: The Politics of Cure and Care in the Making of Alzheimer's Disease." *Social Science & Medicine* 74, no. 5 (2012): 788-95.
- Clarke, Adele .E., Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim, eds. *Biomedicalization: Technoscience, Health, and Illness in the U.S.* Durham, NC:

- Duke University Press, 2009.
- Cohen, Lawrence. *No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things*. Berkeley, CA: University of California Press, 1998.
- Cole, Jennifer. 2001. *Forget Colonialism: Sacrifice and the Art of Memory in Madagascar*. Berkeley, CA: University of California Press.
- Comer, Meryl. *Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's*. New York, NY: HarperCollins, 2015.
- Conrad, Peter. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore, MD: Johns Hopkins University Press, 2007.
- Conrad, Peter, and Joseph W. Schneider. *Deviance and Medicalization: From Badness to Sickness*. Philadelphia, PA: Temple University Press, 1992.
- Coontz, Stephanie Coontz. 1992. *The Way We Never Were: American Families and the Nostalgia Trap*. New York: Basic Books.
- Dalley, Gillian. *Ideologies of Caring: Rethinking Community and Collectivism*. New York, NY: Macmillan, 1996.
- Davis, Lennard J. *Bending over Backwards: Essays on Disability and the Body*. New York, NY: NYU Press, 2002.
- Davis-Floyd, Robbie. *Birth as an American Rite of Passage*. Berkeley, CA: University of California Press, 1992.
- Edwards, Jeanette, Sarah Franklin, Eric Hirsch, Frances Price, and Marilyn Strathern, eds. *Technologies of Procreation: Kinship in the Age of Assisted Conception*. 2nd ed. New York, NY: Routledge, 1999.
- Ehrenreich, Barbara, and Deidre English. *For Her Own Good: 150 Years of the Experts' Advice to Women*. New York, NY: Anchor Press/Doubleday, 1978.
- Epstein, Steven. *Impure Science: Aids, Activism, and the Politics of Knowledge*. Berkeley, CA: University of California Press, 1996.
- Farquhar, Judith, and Margaret M. Lock. "Introduction." In *Beyond the Body Proper: Reading the Anthropology of Material Life*, edited by Margaret M. Lock and Judith Farquhar, 1-16. Durham, NC: Duke University Press, 2007.
- Fleck, Ludwig. *Genesis and Development of a Scientific Fact*. Translated by Frederick Bradley.

- University of Chicago Press, 2012[1935].
- Folstein, Marshal F, Lee N Robins, and John E Helzer. "The Mini-Mental State Examination." *Archives of general psychiatry* 40, no. 7 (1983): 812-12.
- Fox, Patrick. "From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement." *The Milbank Quarterly* (1989): 58-102.
- Franklin, Allan. "Calibration." *Perspectives on Science* 5, no. 1 (1997): 31-80.
- Franklin, Sarah, and Susan McKinnon, eds. *Relative Values: Reconfiguring Kinship Studies*. Durham, NC: Duke University Press, 2001.
- Fraser, Nancy and Linda Gordon. 1993. "Contract versus Charity: Why Is There No Social Citizenship in the United States?" *Socialist Review* 212(3): 45-68.
- Gandy, Sam. "Perspective: Prevention Is Better Than Cure." *Nature* 475, no. 7355 (2011): S15-S15.
- Genova, Lisa. *Still Alice*. New York, NY: Simon & Schuster, 2007.
- Glenn, Evelyn Nakano. "Creating a Caring Society." *Contemporary sociology* 29, no. 1 (2000): 84-94.
- Glenn, Evelyn Nakano. *Forced to Care: Coercion and Caregiving in America*. Cambridge, MA: Harvard University Press, 2010.
- Goffman, Erving. *The Presentation of Self in Everyday Life*. New York, NY: Doubleday, 1959.
- Good, Mary-Jo DelVecchio. "The Biotechnical Embrace." *Culture, medicine and psychiatry* 25, no. 4 (2001): 395-410.
- Gresham, Mary L. "The Infantilization of the Elderly: A Developing Concept." Paper presented at the Nursing Forum, 1976.
- Gross, Jane. "Who Cares for the Caregivers?" *New York Times*, October 14 2008, <http://newoldage.blogs.nytimes.com/2008/10/14/who-cares-for-the-caregivers/>, accessed April 10, 2016.
- Gubrium, Jaber F. *Oldtimers and Alzheimer's: The Descriptive Organization of Senility*. Contemporary Ethnographic Studies. Greenwich, Conn: JAI Press, 1986.
- Gubrium, Jaber F. "Narrative Practice and the Inner Worlds of the Alzheimer's Disease Experience." *In Concepts of Alzheimer's Disease: Biological, Clinical and Cultural*

- Perspectives. Peter J. Whitehouse, Konrad Hauser, and Jesse F. Ballenger, eds. Pp. 181-203. Baltimore, MD: The Johns Hopkins University Press, 2000.
- Guyer, Jane I. "Prophecy and the near Future: Thoughts on Macroeconomic, Evangelical, and Punctuated Time." *American Ethnologist* 34, no. 3 (2007): 409-21.
- Hacking, Ian. *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses*. Cambridge, MA: Harvard University Press, 2002.
- Hagestad, Gunhild O. "Dimensions of Time and the Family." *American Behavioral Scientist* 29, no. 6 (July 1, 1986): 679-94.
- Hagestad, Gunhild O. "On-Time, Off-Time, Out of Time? Reflections on Continuity and Discontinuity from an Illness Process." In *Adulthood and Aging: Research on Continuities and Discontinuities*, edited by Vern L. Bengtson, 204-22. New York, NY: Springer Publishing Company, 1996.
- Hareven, Tamara K. "Family Time and Historical Time." *Daedalus* 106, no. 2 (1977): 57-70.
- Haraway, Donna. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist studies* 14, no. 3 (1988): 575-99.
- Havighurst, Robert J. "Successful Aging." *The Gerontologist* 1, no. 1 (1961): 8-13.
- Herskovits, Elizabeth. "Struggling over Subjectivity: Debates About the "Self" and Alzheimer's Disease." *Medical anthropology quarterly* 9, no. 2 (1995): 146-64.
- Hochschild, Arlie R. *The Managed Heart: Commercialization of Human Feeling, Twentieth Anniversary Edition, with a New Afterword*. Berkeley, CA: University of California Press, 2003[1983].
- Hochschild, Arlie, and Anne Machung. *The Second Shift: Working Families and the Revolution at Home*. New York, NY: Penguin Publishing Group, 2012.
- Holstein, Martha. "Alzheimer's Disease and Senile Dementia, 1885–1920: An Interpretive History of Disease Negotiation." *Journal of Aging Studies* 11, no. 1 (1997): 1-13.
- Hooyman, Nancy R., and Judith Gonyea. *Feminist Perspectives on Family Care: Policies for Gender Justice*. Thousand Oaks, CA: Sage Publications, 1995.
- Hull, Matthew S. "Documents and Bureaucracy\*." *Annual Review of Anthropology* 41 (2012): 251-67.
- Hurd, Michael D, Paco Martorell, Adeline Delavande, Kathleen J Mullen, and Kenneth M

- Langa. "Monetary Costs of Dementia in the United States." *New England Journal of Medicine* 368, no. 14 (2013): 1326-34.
- Illich, Ivan. *Medical Nemesis: The Expropriation of Health*. New York, NY: Bantam Books, 1979.
- Jain, S. Lochlann. "Living in Prognosis: Toward an Elegiac Politics." *Representations* 98, no. 1 (2007): 77-92.
- Jain, S. Lochlann. *Malignant: How Cancer Becomes Us*. Berkeley, CA: University of California Press, 2013.
- Jenkins, Tamara, dir. *The Savages*. 113 min. Hollywood, CA: Fox Searchlight Pictures, 2007.
- Jutel, Annemarie Goldstein. *Putting a Name to It: Diagnosis in Contemporary Society*. Baltimore, MD: Johns Hopkins University Press, 2011.
- Kaufman, Sharon R. *And a Time to Die: How American Hospitals Shape the End of Life*. New York: Scribner, 2005.
- Katz, Sidney. "Assessing Self-Maintenance: Activities of Daily Living, Mobility, and Instrumental Activities of Daily Living." *Journal of the American Geriatrics Society* 31, no. 12 (1983): 721-27.
- Katz, Sidney, Amasa B. Ford, Roland W. Moskowitz, Beverly A. Jackson, and Marjorie W. Jaffe. "Studies of Illness in the Aged: The Index of Activities of Daily Living." *JAMA* 185 (1963): 914-19.
- Katz, Stephen. "Busy Bodies: Activity, Aging, and the Management of Everyday Life." *Journal of aging studies* 14, no. 2 (2000): 135-52.
- Katzman, Robert, and Katherine L. Bick. "The Rediscovery Of Alzheimer Disease During the 1960s and 1970s." In *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*, edited by Peter J. Whitehouse, Konrad Maurer and Jesse F. Ballenger, 104-14. Baltimore, MD: Johns Hopkins University Press, 2000.
- Kittay, Eva Feder. *Love's Labor: Essays on Women, Equality, and Dependency*. New York, NY: Routledge, 1999.
- Kitwood, Tom. "Towards a Theory of Dementia Care: The Interpersonal Process." *Ageing and Society* 13, no. 01 (1993): 51-67.
- Kitwood, Tom. *Dementia Reconsidered: The Person Comes First*. Philadelphia, PA: Open University Press, 1997.

- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York, NY: Basic Books, 1988.
- Kleinman, Arthur. "The Biocultures of Caregiving: A Commentary on 'Biocultures'." *New Literary History* 38, no. 3 (2007):593-599.
- Kleinman, Arthur. "Caregiving: The Odyssey of Becoming More Human." *The Lancet* 373, no. 9660 (2009):292-293.
- Kleinman, Arthur. "Caregiving: The Divided Meaning of Being Human and the Divided Self of the Caregiver." In *Rethinking the Human*, edited by J. Michelle Molina, Donald K. Swearer and Susan Lloyd McGarry. Cambridge, MA: Center for the Study of World Religions, Harvard Divinity School, 2010.
- Lamb, Sarah. *White Saris and Sweet Mangoes: Aging, Gender, and Body in North India*. Berkeley, CA: University of California Press, 2000.
- Lamb, Sarah. "Permanent Personhood or Meaningful Decline? Toward a Critical Anthropology of Successful Aging." *Journal of aging studies* 29 (2014): 41-52.
- Law, John, and Vicky Singleton. "Object Lessons." *Organization* 12, no. 3 (2005): 331-55.
- Lawton, M. Powell, and Elaine M. Brody. "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living." *The Gerontologist* (1969): 179-86.
- Leavitt, Sarah. *Tangles*. Calgary, Alberta, CA: Freehand Books, 2010.
- Leibing, Annette. "Entangled Matters—Alzheimer's, Interiority, and the 'Unflattening' of the World." *Culture, Medicine, and Psychiatry* 32, no. 2 (2008): 177-93.
- Levine, Carol. *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*. New York, NY: United Hospital Fund of New York, 2004.
- Levitsky, Sandra R. *Caring for Our Own: Why There Is No Political Demand for New American Social Welfare Rights*. New York, NY: Oxford University Press, 2014.
- Liu, Yin, Kyungmin Kim, and Steven H. Zarit. "Health Trajectories of Family Caregivers: Associations with Care Transitions and Adult Day Service Use." *Journal of Aging and Health* 27, no. 4 (June 1, 2015): 686-710.
- Lock, Margaret. *The Alzheimer Conundrum: Entanglements of Dementia and Aging*. Princeton, NJ: Princeton University Press, 2013.

- Lyman, Karen A. "Bringing the Social Back In: A Critique of the Biomedicalization of Dementia." *The Gerontologist* 29, no. 5 (1989): 597-605.
- Mace, Nancy L., and Peter V. Rabins. *The 36-Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias, and Memory Loss in Later Life*. Baltimore, MD: Johns Hopkins University Press, 2006.
- Mangialasche, Francesca, Alina Solomon, Bengt Winblad, Patrizia Mecocci, and Miia Kivipelto. "Alzheimer's Disease: Clinical Trials and Drug Development." *The Lancet Neurology* 9, no. 7 (2010): 702-16.
- Marcoux, Jean-Sebastien. 2001. The 'Casser maison' ritual: constructing the self by emptying the house. *Journal of Material Culture*, 6(2),213-235.
- Markut, Linda A., and Anatole Crane. *Dementia Caregivers Share Their Stories: A Support Group in a Book*. Nashville, TN: Vanderbilt University Press, 2005.
- Martinson, Marty, and Clara Berridge. "Successful Aging and Its Discontents: A Systematic Review of the Social Gerontology Literature." *The Gerontologist* 55, no. 1 (2015): 58-69.
- Mattingly, Cheryl. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. New York, NY: Cambridge University Press, 1998.
- Mattingly, Cheryl, and Linda C. Garro. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley, CA: University of California Press, 2000.
- Mauss, Marcel. "A Category of the Human Mind: The Notion of Person, the Notion of Self." In *The Category of the Person: Anthropology, Philosophy, History*, edited by Michael Carrithers, Steven Collins and Steven Lukes, 1-25. Cambridge: Cambridge University Press, 1985[1938].
- May, Elaine Tyler. 1988. *Homeward Bound: American Families in the Cold War Era*. New York: Basic Books.
- Miller, Daniel. 2001. *Home possessions: material culture behind closed doors*. Oxford: Berg Books.
- McKhann, Guy, David Drachman, Marshall Folstein, Robert Katzman, Donald Price, and Emanuel M. Stadlan. "Clinical Diagnosis of Alzheimer's Disease Report of the NINCDS-ADRDA Work Group\* under the Auspices of Department of Health and Human Services Task Force on Alzheimer's Disease." *Neurology* 34, no. 7 (1984): 939-39.
- McKhann, Guy M, David S Knopman, Howard Chertkow, Bradley T Hyman, Clifford R Jack, Claudia H Kawas, William E Klunk, *et al.* "The Diagnosis of Dementia Due to Alzheimer's Disease: Recommendations from the National Institute on Aging-

- Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease." *Alzheimer's & dementia* 7, no. 3 (2011): 263-69.
- McKinnon, Susan, and Fenella Cannell. *Vital Relations: Modernity and the Persistent Life of Kinship*. Santa Fe, NM: School for Advanced Research Press, 2013.
- McLean, Athena. *The Person in Dementia: A Study in Nursing Home Care in the US*. Orchard Park, NY: Broadview Press, 2007.
- Mitnick, Sheryl, Cathy Leffler, Virginia L Hood, Professionalism American College of Physicians Ethics, and Human Rights Committee. "Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships." *Journal of general internal medicine* 25, no. 3 (2010): 255-60.
- Mol, Annemarie. *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press, 2002.
- Morton, Christopher. 2007. Remembering the House: Memory and Materiality in Northern Botswana. *Journal of Material Culture*, 12(2), 157-179.
- Moreira, Tiago. "Now or Later? Individual Disease and Care Collectives in the Memory Clinic." In *Care in Practice: On Tinkering in Clinics, Homes and Farms*, edited by Annemarie Mol, Ingunn Moser and Jeanette Pols, 119-40. Bielefeld, Germany: transcript, 2015.
- Moser, Ingunn. "Making Alzheimer's Disease Matter. Enacting, Interfering and Doing Politics of Nature." *Geoforum* 39, no. 1 (2008): 98-110.
- Myerhoff, Barbara. *Number Our Days*. New York, NY: Touchstone, 1980.
- Neugarten, Bernice L. "Personality and the Aging Process." *The Gerontologist* (1972).
- Neugarten, Bernice L. "Time, Age, and the Life Cycle." *American Journal of Psychiatry* 136, no. 7 (1979): 887-94.
- Noddings, Nel. *Caring, a Feminine Approach to Ethics & Moral Education*. Berkeley, CA: University of California Press, 1984.
- Petersen, Barry. *Jan's Story: Love Lost to the Long Goodbye of Alzheimer's*. Lake Forest, CA: Behler Publications, LLC, 2010.
- Peterson, Peter G. "Gray Dawn: The Global Aging Crisis." *FOREIGN AFFAIRS-NEW YORK*-78 (1999): 42-55.
- Pohlman, Elizabeth Grace. "Ethics and Politics of Caring and Curing: The Case of Down

- Syndrome and Alzheimer Disease." PhD Dissertation, University of California, San Francisco and University of California, Berkeley, 2010.
- Polley, Sarah, dir. *Away From Her*. 110 min. Hollywood, CA: Lions Gate Films, 2006.
- Post, Stephen G. *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying*. Baltimore, MD: Johns Hopkins University Press, 2000.
- Post, Stephen G. "The Concept of Alzheimer's Disease in a Hypercognitive Society." In *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*, edited by Peter J. Whitehouse, Konrad Maurer and Jesse F. Ballenger: Johns Hopkins University Press, 2000.
- Rapp, Rayna. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York, NY: Routledge, 1999.
- Reisberg, Barry, Steven H Ferris, Mony J de Leon, Elia Sinaiko Emile Franssen, Alan Kluger, Pervez Mir, Jeffrey Borenstein, *et al.* "Stage-Specific Behavioral, Cognitive, and in Vivo Changes in Community Residing Subjects with Age-Associated Memory Impairment and Primary Degenerative Dementia of the Alzheimer Type." *Drug Development Research* 15, no. 2-3 (1988): 101-14.
- Reisberg, Barry, Emile H Franssen, Syed Mahmood Hasan, Isabel Monteiro, Istvan Boksay, Liduin EM Souren, Sunnie Kenowsky, *et al.* "Retrogenesis: Clinical, Physiologic, and Pathologic Mechanisms in Brain Aging, Alzheimer's and Other Dementing Processes." *European Archives of Psychiatry and Clinical Neuroscience* 249, no. 3 (1999): S28-S36.
- Reverby, Susan. *Ordered to Care: The Dilemma of American Nursing, 1850-1945*. Cambridge: Cambridge University Press, 1987.
- Riessman, Catherine Kohler. "Women and Medicalization: A New Perspective." *Social policy* 14, no. 1 (1983): 3-18.
- Robbins, Joel. "Beyond the Suffering Subject: Toward an Anthropology of the Good." *Journal of the Royal Anthropological Institute* 19, no. 3 (2013): 447-62.
- Rosalyn Carter Institute for Caregiving. "Averting the Care Crisis: Why We Must Act Now." Georgia: Rosalyn Carter Institute for Caregiving, 2010.
- Rosenberg, Charles E. *Our Present Complaint: American Medicine, Then and Now*. Baltimore, MD: Johns Hopkins University Press, 2007.
- Rowe, John W, and Robert L Kahn. "Human Aging: Usual and Successful." *Science* 237, no. 4811 (1987): 143-49.

- Rowe, John W, and Robert L Kahn. "Successful Aging." *The gerontologist* 37, no. 4 (1997): 433-40.
- Rowe, John W, and Robert L Kahn. "Successful Aging: The Macarthur Foundation Study." *New York: Pantheon* (1998).
- Sabat, Steven R. *The Experience of Alzheimer's Disease: Life through a Tangled Veil*. New York, NY: Wiley, 2001.
- Sabat, Steven R, and Rom Harré. "The Construction and Deconstruction of Self in Alzheimer's Disease." *Ageing and Society* 12, no. 04 (1992): 443-61.
- Satz, Paul, Michael A. Cole, David J. Hardy, and Yuri Rassovsky. "Brain and Cognitive Reserve: Mediator(S) and Construct Validity, a Critique." *Journal of Clinical and Experimental Neuropsychology* 33, no. 1 (2011/01/05 2011): 121-30.
- Saunders, Barry F. *CT Suite: The Work of Diagnosis in the Age of Noninvasive Cutting*. Durham, NC: Duke University Press, 2008.
- Schulz, Richard, and Lynn M Martire. "Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies." *The American journal of geriatric psychiatry* 12, no. 3 (2004): 240-49.
- Seaman, Aaron. "The Moment of 'Huh?'" *Medicine Anthropology Theory*, (11 March 2015). Electronic publication: <http://medanthrotheory.org/read/4767/moment>, accessed July 13, 2016.
- Shah, Nayan. *Contagious Divides: Epidemics and Race in San Francisco's Chinatown*. Berkeley, CA: University of California Press, 2001.
- Shenk, David. *The Forgetting: Alzheimer's: Portrait of an Epidemic*. New York, NY: Knopf Doubleday Publishing Group, 2003.
- Silverman, Chloe. *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton, NJ: Princeton University Press, 2012.
- Soler, Léna, Frédéric Wieber, Catherine Allamel-Raffin, Jean-Luc Gangloff, Catherine Dufour, and Emiliano Trizio. "Calibration: A Conceptual Framework Applied to Scientific Practices Which Investigate Natural Phenomena by Means of Standardized Instruments." *Journal for general philosophy of science* 44, no. 2 (2013): 263-317.
- Sontag, Susan. *Illness as Metaphor and Aids and Its Metaphors*. New York, NY: Farrar, Straus and Giroux, 2013[1977/1988].

- Staff of the Benjamin Rose Hospital. "Multidisciplinary Studies of Illness in Aged Persons, Ii. A New Classification of Functional Status in Activities of Daily Living." *Journal of Chronic Disease* 9, no. 1 (1959): 55-62.
- Starr, Paul. *The Social Transformation of American Medicine*. New York, NY: Basic Books, 1982.
- Stern, Yaakov. *Cognitive Reserve: Theory and Applications*. New York, NY: Taylor & Francis, 2013.
- Taylor, Janelle S. "On Recognition, Caring, and Dementia." *Medical Anthropology Quarterly* 22, no. 4 (2008): 313-35.
- Taylor, Richard. *Alzheimer's from the inside Out*. Health Professions Press, 2007.
- Thompson, Charis. "Strategic Naturalizing: Kinship in an Infertility Clinic." In *Relative Values: Reconfiguring Kinship Studies*, edited by Sarah Franklin and Susan McKinnon. Durham, NC: Duke University Press, 2001.
- Thompson, Charis. *Making Parents: The Ontological Choreography of Reproductive Technologies*. Cambridge, MA: MIT Press, 2005.
- Tronto, Joan C. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York, NY: Routledge, 1993.
- US Congress, Office of Technology Assessment. *Confused Minds, Burdened Families: Finding Help for People with Alzheimer's & Other Dementias*, OTA-13A-403. Washington, D.C.: U.S. Government Printing Office (1990). Electronic Document, [http://govinfo.library.unt.edu/ota/Ota\\_2/DATA/1990/9010.PDF](http://govinfo.library.unt.edu/ota/Ota_2/DATA/1990/9010.PDF), accessed December 20, 2009.
- U.S. Department of Health and Human Services. 2009. *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging*. Washington, DC: U.S. Department of Health and Human Services.
- US Senate Special Committee on Aging. *Until There's a Cure: How to Help Alzheimer's Patients and Families Now*, Second Session, December 8, 2010, 2011.
- Weisz, George. *Chronic Disease in the Twentieth Century: A History*. Baltimore, MD: Johns Hopkins University Press, 2014.
- Wertz, Richard W., and Dorothy C. Wertz. *Lying-In: A History of Childbirth in America*. New York, NY: Free Press, 1977.

- Weston, Kath. *Families We Choose: Lesbians, Gays, Kinship*. New York, NY: Columbia University Press, 1991.
- Williams, Simon J, and Michael Calnan. "The 'Limits' of Medicalization?: Modern Medicine and the Lay Populace in 'Late' Modernity." *Social science & medicine* 42, no. 12 (1996): 1609-20.
- Witchel, Alex. *All Gone: A Memoir of My Mother's Dementia. With Refreshments*. New York, NY: Penguin Publishing Group, 2012.
- Young, Allan. *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder*. Princeton, NJ: Princeton University Press, 1995.
- Zarit, Steven H., Nancy K. Orr, and Judy M. Zarit. *The Hidden Victims of Alzheimer's Disease: Families under Stress*. New York, NY: NYU Press, 1985.
- Zelizer, Viviana A. *The Purchase of Intimacy*. Princeton, NJ: Princeton University Press, 2005.
- Zola, Irving Kenneth. "Medicine as an Institution of Social Control." *Sociological Review* 20, no. 4 (1972): 487-504.
- Zola, Irving Kenneth. *Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations*. Temple University Press, 1983.