

On Recognition, Caring, and Dementia

The onset of dementia raises troubling questions. Does the person with dementia still recognize you? If someone cannot recognize you, can they still care about you? This essay takes such questions as the entry point for a broader inquiry into recognition, its linkages to care, and how claims to social and political “recognition” are linked to, or premised on, the demonstrated capacity to “recognize” people and things. In the words and actions of her severely impaired mother, the author finds guidance toward a better, more compassionate question to ask about dementia: how can we best strive to “keep the cares together”?

My mother is living with progressive dementia. Since my father died, about three and a half years ago now, I have been very involved in her care.

I am listening for it. Because I am writing these words rather than speaking them, I cannot hear your response, but I am listening for the question that, as I have learned, always comes.

I speak about my mother and her condition to friends, coworkers, and others around me, as openly as I would about any other important aspect of my family life. Over time, I have noticed that at the mention of dementia, memory loss, or Alzheimer's, *everyone*, almost without exception, responds with some version of the same question: “Does she recognize you?”

There are variants, of course:

“Does she still know who you are?”

“She’s aware of you, though?”

“But at least she still knows your name, right?”

However it may be phrased, the question is always whether my mother *recognizes* me, meaning: can she recite “the facts” of who I am, what my name is, and how I am related to her?

Frequent repetition has made this question sound strange to me. As a daughter, I have learned that when someone you love asks you the same question over and over again, it is probably a symptom of dementia. As an anthropologist, however, I am convinced that when *many* people ask the same question over and over again, it is probably a symptom of something important and unresolved about social life. If the mere mention of dementia very regularly calls forth particular kinds of questions about “recognition,” this seems to me a social fact worthy of reflection.

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In this essay, I take such questions as the entry point for an inquiry into recognition, its linkages to care, and what these linkages imply—for people living with dementia, and for the rest of us, the “Temporarily Able-Brained” (Friedell 2003) who share a world with them today, and who may ourselves join their ranks in the future.

The research on which I report here is of the decidedly unchosen variety, thrust on me by life-changing losses that I would have avoided if I could, but from which I have learned a great deal nonetheless. My training as a medical anthropologist has moved me, through all that has happened, to keep notes and record observations about conversations, events, and experiences that seemed important, to collect materials and documents that seemed relevant, and to search out and read scholarly analyses as well as personal accounts of dementia. The account that follows is thus “autoethnographic,” in the sense that it addresses certain aspects of the social world that have become visible and interesting to me by virtue of my particular position as daughter of a lovely and beloved mother with advanced dementia. It is an attempt to tell the truth as I see it, from where I now stand.

“Does she recognize you?”

It is tempting to look beyond and behind this question for the intentions that motivate any particular person to ask it. I believe it is worth resisting the impulse to jump to explanations pitched at the level of individuals, however, at least long enough to ponder the very specific and widely shared form that this question takes, as a query about “recognition.”

The philosopher Paul Ricoeur, in *The Course of Recognition* (2005), seeks to develop a philosophical approach to “recognition” that could embrace the full range of the term’s many meanings. Beginning from the definitions listed in dictionaries, Ricoeur considers the points of etymological and semantic overlap that link one sense of “recognition” to another. Underlying this proliferation of meanings, he identifies three significant semantic clusters, which he construes as moments in a dialectic that begins from recognition as identification (of things), moves through self-recognition, and finally concludes with recognition by an Other. As he shows, critical transformations take place in the course of the movement from the first of these moments to the last: “recognition” changes from the active to the passive voice, as it moves from a cognitive and intellectual matter to an ethical and political one. What begins in the sovereign self’s active intellectual “recognition” of external objects ends in the socially and politically embedded subject’s passive receipt of “recognition” granted by others.

It is the broad scope of Ricoeur’s framing of “recognition” that I find so helpful. When a friend or acquaintance or coworker asks me, “Does she recognize you?” he or she is, in Ricoeur’s terms, giving voice to the first of the three distinct “moments” in the “course of recognition”: the question concerns my mother’s ability, as a sovereign self, to actively draw intellectual distinctions among the objects and people around her. I have come to think, however, that also at stake here is Ricoeur’s third and final “moment,” when the subject is granted social and political recognition by others.

Ordinarily in my life, when someone asks me a question that I find baffling or rude, I respond with a query of my own: “Why do you ask?” Ricoeur’s analysis helps me to similarly turn around the question that people are always asking me about my mother, and respond with a query of my own. How are claims to social and political “recognition” linked to, or premised on, the demonstrated capacity to “recognize” people and things? When elderly people with dementia suffer cognitive changes, how do these get invested with decisive importance in determining whether and how they are (or are not) granted “recognition” as fully social persons and members of a community?

When everyone keeps asking me “Does she recognize you?” I believe the question really is—or should be—“Do you, do we, recognize *her*? Do we *grant her recognition*?”

“Does she recognize you?”

I was first led to ponder at length the meanings of the term *recognition* by the simple fact that I found this question both ubiquitous and quite difficult to answer.

My Mom is always glad to see me. Does she still know my name? It has been years since I’ve heard her say it. Not long ago, she pointed to a painting of her father that hangs in her room, and said, “That’s my Dad.” And at least up until a year or so ago, she referred by name to Chuck, my father, to whom she was married for forty-nine years until his death. But I have heard her speak no other names for a very long time. At this point, my mother has considerable difficulty finding all kinds of words, let alone names. When words do come, they disperse too quickly, and rarely hang together long enough to form a full sentence. I do not expect that I will ever again hear my name spoken in my mother’s voice.

Even before she became impaired, however, my mother rarely ever called me Janelle. That was the name she gave me at birth, and it has always been the name I use outside my family, but over the years my Mom gave me many other names as well. At home I was Nellie, or sometimes Nelle-Belle. But usually, I was Sweetie, Honey, Kid, Pumpkin, Friend, Pest, or any one of many other silly nicknames.

And now, I am Stranger. One day some months ago, I walked into the activity room of the secure dementia unit where my mother now lives, and found her sitting at a table with three other white-haired ladies and two pretty young aides, playing some version of poker with a set of enormous playing cards. Mom saw me, and a smile slowly spread over her face, as she raised her hand to point at me, and said: “Well, hello there, Stranger!” It’s a name that one would use, of course, only for someone who is very familiar. When she calls me Stranger, I know that I am no stranger to her.

Not only is it hard to know whether my mother “recognizes” me, in the narrow sense of remembering my name, but the question itself also seems to me more and more irrelevant. I know that it is out of concern for me, as well as for my mother, that well-meaning friends and acquaintances ask me this question. 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. Those who have little firsthand experience with dementia tend, I think, to imagine it as a more or less purely cognitive loss of a store of remembered facts, manifested in a loss of the

ability to recite names and dates and other bits of information. Knowing the names of one's own children presents itself, in this view, as the most obvious and dramatic of what Elinor Fuchs calls the "stills." Fuchs writes:

One can measure the advance of dementia by the "stills." The social worker will ask the *still* questions: Does she *still* feed herself? *Good!* Still chew? *Good!* Still toilet? Well, that's to be expected. And we have ours: Still like to dress up? Get her hair done? Her nails? Still hang on to her French and German? Yes, a few words, pretty good accent. Still play the piano? Oh yes, the "Anniversary Waltz," over and over. Still like parties? Oh-ho, *does she ever!* [Fuchs 2005:4]

Yet it is worth noting that the ability to remember names does not even merit a place in Fuchs's own list of "stills." Set in the context of questions about the degree to which a person is able to eat, bathe, dress, or speak, and so on, whether he or she remembers names may not seem so important.

For those who have some personal experience with dementia, the "stills" are paralleled by the "firsts." The first time my mother repeated the same question several times in the course of a short telephone conversation, almost nine years ago now, I wept inconsolably at the prospect of, as I then feared, "losing her." In retrospect, that first "first" seems to me quite innocuous, and my response to it rather overwrought. I marvel that such a minor impairment once seemed to me so terrifying. Other "firsts" that have come since have been harder. The first time after my father's death that Mom asked where he was. The first time I had to make a decision about her medications. The first time she tried to sign her own name and could not. The first time she needed my help in the shower.

Yet it bears saying that not all of the "stills" and the "firsts" necessarily tell a grim story of unremitting decline, loss, humiliation, and disappearance. Despite all the changes she has been through, my mother "still" is in many ways the cheerful, affectionate person I have always known her to be. Mom still enjoys gentle joking and teasing, as she always has. She still enjoys being around people, still beams radiantly at small children when she sees them, still enjoys the give and take of conversation. And for my part, I must say that some of the "firsts" have been tender moments that I cherish. The "first" time since my early childhood that my Mom and I walked down the street holding hands. The first time I tucked her into bed at night with her stuffed animals all around her. The first time (in at least forty years) that we sang together a loud and unabashed, if slightly out-of-tune, chorus of "She'll Be Coming 'Round the Mountain."

Amid so many "stills" and "firsts," many sad and painful, some sweet and funny, the more I become involved with the practicalities of caring for my mother, the weirder it seems to me that everyone else seems to care only about the one very narrow question of whether she still "recognizes" me in the very specific sense of being able to identify me by name.

"Does she recognize you?"

The weirdness of the question becomes more obvious when one pauses to consider the procedure that would be required to answer it.

Imagine that you came upon two people, and one of them is urgently questioning the other: “*What is my name? Who am I? How old am I? How do we know each other?*” Would you not assume that it is the *questioner*, rather than the one being questioned, who suffers from a loss of memory?

I don’t *need* my mother to tell me my name, or how I am related to her. I already *know* these things. And I *know*, furthermore, that she suffers cognitive losses—that’s just what it means to have dementia. So why, then, would I make a point of asking her these questions that I *know* she cannot possibly answer? To do so seems to me rude by all normal standards of social intercourse, if not downright mean. I can’t bring myself to do it. I guess you could say that my mother raised me better than that.

But of course, by the time one embarks on such interrogations, one is already acting on the judgment that “normal standards of social intercourse” do not apply. And in many ways they really *cannot* apply to people with dementia, who often speak or behave weirdly, and in that sense are rude, simply because their impairment prevents them keeping straight the rules of social intercourse and the sense of how to act within them. Still, I find it remarkable that for many people whose cognitive functioning is *not* impaired, who *can* still observe social niceties, the mere suspicion that someone else *might* suffer dementia seems to justify, or even require, that they suspend all the rules and habits learned over a lifetime, about how to treat another person politely and with kindness. Lauren Kessler recalls:

I always corrected her when she called me Judy (her sister). Every time I visited, I took down the framed photographs from her dresser—the ones I had brought in to remind her of her family—pointed to each, and quizzed her. “You know who this is, don’t you, Mom?” Of course, she didn’t. So I told her, again and again, each visit, who was who. And then quizzed again . . . Thinking back on this now, I am appalled at my insensitivity. What did I think I was doing? After months of reality orientation, I managed to accomplish only two things: I made myself miserable, and I made my mother irritable. [Kessler 2007:88]

Kessler is unusual only in the degree of critical reflection with which she now recalls these matters. The kind of grilling to which she once subjected her mother is common—common enough that one very nice little book offering practical tips on how to talk to a family member or friend with Alzheimer’s specifically advises: “Don’t ask them to tell you what your name is, or how you are related to them” (Strauss 2001:95).

“Does she recognize you?”

When my friends inquire whether my mother still recognizes me, they speak out of sympathetic concern for me, and the emotional suffering they assume I must experience, from what is regularly described as “the horror of Alzheimer’s.” One component of this horror is an ethical judgment.

Not only is it tragic, but it is *wrong* for a person to forget their close relations, especially family relations. Philosopher Avishai Margalit, in a book entitled *The Ethics of Memory*, asks:

Is there an ethics of memory? . . . Are we obligated to remember people and events from the past? If we are, what is the nature of this obligations. Are remembering and forgetting proper subjects of moral praise or blame?
[Margalit 2002:7]

Margalit concludes that there is an *ethics* of memory, but very little *morality* of memory. In his argument, ethics pertains to “thick” social relations with those nearest and dearest to us in our lives, whereas morality concerns “thin” social relations with people to whom we are not bound by any special ties, “the stranger and the remote.” Shared memory is, he contends, “the cement that holds thick relations together.”

Memory of names is an especially important ingredient of that cement. *The Ethics of Memory* begins with the story of an Israeli army commander who publicly admitted that he had forgotten the name of a soldier in his unit who was killed under his command. His comment drew responses of angry outrage because, Margalit explains, remembering the name of the soldier is just a metonym for remembering the young soldier himself—it is remembering the person that is important. Remembering the person is important because without it, caring is not possible:

What is at stake here is the officer’s *caring* . . . The relation between memory and caring . . . is, I maintain, an internal relation—a relation that could not fail to obtain between these two concepts since memory is partly constitutive of the notion of care. If I care for someone or for something, and then I forget that person or that thing, this means that I have stopped caring for him or it. [Margalit 2002:27–28]

For Margalit, “caring” is primarily an attitude toward others. He works to specify just what kind of attitude it is, and how it differs from others: caring “suggests regard for other people” (2002:31), it “is concerned with their wants and needs” (2002:34), it “is a selfless attitude” (2002:35), and it is “a demanding attitude toward others” because “what we find hard is the *attention* that is implied by caring” (2002:33). However we may specify it, though, “caring” remains a subjective and internal state of mind and feeling of a discrete individual, and one that is premised on a capacity for “recognition” in its narrowly cognitive sense.

On Margalit’s account, if my mother has forgotten my name, and does not “recognize” me, then she has surely stopped “caring” about me.

“Does she recognize you?”

I am not so convinced that the inability to remember names necessarily means that a person with dementia cannot “recognize” or “care” about other people, for reasons I will explore below. But very often, it does mean that other people stop “recognizing” and “caring” about *them*.

When my father died, five hundred people attended his memorial service. Many of them were people I did not know, part of the large circle of friends, acquaintances, colleagues, and former students he had come to know over the decades that he worked at a Seattle-area public high school as a principal with a very hands-on administrative style and an outgoing, friendly demeanor. Many of these people knew my mother, however, and some were longtime friends of my parents whom I recognized, by face or at least by name, from my earliest childhood. Others were people they knew through the various groups in which they had taken part: the investment club, the monthly discussion “salon,” the group of people who walked with them every morning at the local mall, and others. Some were primarily my mother’s friends: neighbors, women she had worked with at her various office jobs over the years, mothers of the friends of some of her children with whom she had become close, old friends from her college days. On that day, united with her in grief, all of these people greeted Mom with hugs, and tears, and condolences.

And then they disappeared. A few friends did come to see Mom at least once or twice, in the first months after Dad died. But those few visits aside, whenever I scanned the “guest sign-in” sheet at the facility where Mom lived, I saw—no one. Two and a half years later, when it came time to move my mother into a specialized dementia unit located in a different assisted-living facility, I wrote to all of my parents’ friends for whom I had any contact information, updating them on her situation, letting them know her new address, telling them that she would doubtless enjoy receiving visits, asking them to please forward my note to anyone else I may have missed, and to please contact me with any questions they might have. No one replied.

Only one friend remains present in my mother’s life. Every month or two, Eli Davis drives an hour and a half from her home to Seattle to visit Mom, bringing treats, and hugs, and her perennially cheerful self, even prearranging with the staff to lead a storytelling session for all the dementia-ward residents. I love her dearly for it—and I wonder: where are the others? Where are the couples with whom my parents socialized, the women with whom Mom spent hours and hours on the phone all through my childhood? What has become of all their friends? I think about the individual friends of my parents whom I know; each one is a warm, funny, kind person. The sad fact is, however, that as a group, they have abandoned her.

This should not surprise me as much as it has. It is, perhaps, hardly fair to expect friends to step up to challenges from which even close kin often shrink. The same may not be true everywhere (and I venture to hope that further life experience may prove it untrue here too), but it seems to me that middle-class U.S. friendships are not generally expected to bear the weight of deep and diffuse obligations to care. More like pleasure crafts than life rafts, they are not built to brave the really rough waters—and these are rough, corrosive, bitter waters indeed. Dementia seems to act as a very powerful solvent on many kinds of social ties. I doubt that many friendships survive its onset (and, perhaps tellingly, I have been unable to locate any published research about friendships and dementia).

Often, in the social world that my parents (and I) inhabit, friendships are grounded in shared experiences of dealing with the practicalities of life, as

“consociates” who work in the same office, are enrolled in the same institution, pick up kids at the same daycare, and so forth, and tend to fade away once those realities are no longer shared (Plath 1980). Once my mother was retired from work, her children grown up and gone, many such connections atrophied, and she formed few new ones. As her capacities diminished, her social world contracted severely, until it centered almost exclusively (and rather oppressively) on my father.

Friendships in this social world are also built up and sustained through ongoing exchanges of invitations, confidences, favors, gifts, cards, and the like. As Ricoeur discusses, “the logic of giving gifts usually entails reciprocity, which is minimally evident in gratitude and more often demands a return in kind” (Connolly 2007:142). When friendship is grounded in reciprocity, then a person who no longer can engage in the usual social exchanges is difficult to “recognize” any longer as a friend. At my father’s memorial, I saw one of my parents’ old friends for the first time in many years, and explained to her briefly that Mom has what seems to be Alzheimer’s. She exclaimed, “Yes, well, I haven’t gotten a *Christmas* card from her in *years!*” She still sounded quite indignant.

The fact of my mother’s having moved into an institution may also go far toward explaining her social abandonment. The facility where my siblings and I placed her after our father’s death was not a nursing home, but a “retirement community” catering to the wealthy and the well insured, where only a few residents were impaired, and Mom had her own pleasant little apartment furnished with her own belongings. The place had more the feel of a college dormitory than of a scary medical institution. Still, any medical institutionalization arguably entails a form of “social death.” Writing about Alzheimer’s units in nursing homes, J. Neil Henderson describes this view:

When a person is institutionalized, he or she experiences a process of mortification (Goffman 1961). The root *mort*, as in *death*, is not accidental in Goffman’s use of *mortification* to characterize the effect of placement . . . When a person is extracted from home because of dependencies that interrupt his or her ability, or his or her family’s ability, to cope with the exigencies of life, the nursing home placement process becomes step one in a double burial ritual . . . The now-institutionalized person’s psychosocial self is slain at the nursing home door. At this point, the sometimes lengthy step two of the double burial ritual begins. Rather than lie supine on the burial scaffold, as in some cultures, the patient languishes in long-term patienthood until biological functions cease, at which time the second, and final, burial occurs. [Henderson 2003:155]

Not only friends but even their close family members often virtually abandon elderly people who are institutionalized with dementia. The vast majority visit them only briefly and occasionally (Yamamoto-Mitani et al. 2002). And even among family who serve as primary caregivers for people with dementia, “in practice, the ability to recognise others appears to be the most important determinant of whether or not social death occurs” (Sweeting and Gilhooly 1997).

“Does she recognize you?”

After the inevitable question comes, very often, the anecdote. It takes the form of a story about an encounter with someone who does not remember them. Failure to remember a name almost always serves as the punch line:

“ . . . but I don’t really think she even knew the children’s names.”

“ . . . and then I realized that she didn’t even remember me at all.”

I know that the people who tell me these stories do so out of a sympathetic impulse, but I am always left somewhat at a loss. What am I supposed to say? Usually I mumble some sort of awkward defense of the person, “Well, yeah, she probably has some memory loss . . . I’m sure she can’t help it.”

Over time, I have come to think that what is important about these stories is the way that evidence of dementia always serves to *end* them. It is as if someone with dementia never *could* any longer be part of any story that might continue—and if the life *story* is over, then the life must be over too. More than once, some compassionate interlocutor has remarked to me how difficult it must be to have lost both my father and my mother. I find myself having to insist: “But I have not lost my mother, she is not dead.”

It is not insignificant, I think, that the term *Alzheimer’s* (with which all forms of dementia are commonly equated) is so frequently conjoined with the word “horror.” When it comes to speaking or writing about dementia, horror seems to be the default genre. A person you love, and to whom you are bound by unbreakable ties, turns out to be someone you do not know at all, who does not “care” about you and may even seek to harm you: this is the classic gothic plot. It surfaces everywhere. To take just one example, consider this passage from Stephen Holden’s *New York Times* review of Bille August’s 2002 film, *A Song for Martin*:

Like “Iris,” “A Song for Martin” unblinkingly focuses on the special horror of Alzheimer’s as Barbara helplessly watches her husband turn into a stranger and disappear before her eyes. [Holden 2002: E13]

Or, alternatively, a person dies but their body lives on: this is the basic zombie story. In an article titled “Death in Slow Motion: A Descent Into Alzheimer’s,” which I read in *Harper’s* magazine around the time I first began to use the term *Alzheimer’s* in connection with my own mother, Eleanor Cooney described her mother in terms strongly reminiscent of the zombie story:

I grieve for her exactly as if she’d died. She’s gone, I’ve lost her, but I’m still responsible for her living, breathing body and the ghosts in her head . . . [Cooney 2001:57]

Even organizations that advocate for people with Alzheimer’s fall into horror stories. The Dallas chapter of the Alzheimer’s Association, on its webpage, seeks to spur potential donors into action by evoking images of fearsome body snatchers coming to get you:

It's a nightmare. And you can't wake up . . . Alzheimer's will strike 986 more Americans today. And tomorrow. We don't know who will be in that group of victims. It could be someone you know. Someone in your family. Your closest friend. It could be you. We just don't know. We know this: 986 more will be taken today, and every day, until we stop it! [Greater Dallas Chapter 2007]

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.

Such narratives are not "mere" stories. A caregiver's judgment that a person with dementia is "socially dead" does very real harm, when it leads them to ignore the person with dementia, or to treat him or her in dehumanizing ways. One of the caregivers interviewed by Helen Sweeting and Mary Gilhooly, in their interview-based study of "dementia and the phenomenon of social death," described to them his wife and how he treats her:

I suppose people would say it's like living with the living dead . . . She doesn't speak, she does nothing, she just sits there . . . it's very easy, really, she's just a big baby . . . I mean you're sitting there ignoring her basically . . . you know you've got to toilet her and things like that . . . but it's not as if you can sit beside her and talk and try to get her to smile—I've got beyond that. [Sweeting and Gilhooly 1997:105]

Indeed, just how far "beyond that" this man has gotten becomes all too clear in his description of how he leaves his wife tied to the toilet, when he wants to go out of the house for a while. [Sweeting and Gilhooly 1997:105]

In the case of hospitalized people who are attached to various kinds of life-sustaining technologies, the judgment that a person with dementia is "as good as dead" may become a self-fulfilling prophecy, when it serves as "a rationale for facilitating death" (Kaufman 2005:23) and leads to decisions that allow death to happen. As Sharon Kaufman notes, the construction of dementia as "a condition both of death-in-life and of life-in-death" (2005:23) finds expression in the clinical context, in the contradictory statements and stances of medical professionals toward dementia-near-death in hospital settings.

Physicians sometimes unwittingly offer contradictory directives to families, and a kind of doublespeak . . . revolves around the mystery of *life* . . . It emerges in the language that physicians use to explain physiological decline, the absence of beneficial treatments, and the role dementia plays in the nearness to death. It takes the following shape: "Your mother is not actually (or completely) dead, or dead yet, but neither is she alive." Or, "She's not really alive, but we can keep her alive a bit longer." Or, "He has no

meaningful life, but we can continue to take care of him.” Practically, *life* and *death* merge in this language. [Kaufman 2005:40]

The single term *dementia*, it is worth noting, embraces a very wide range of different conditions and degrees of impairment. The hospitalized people on life support whose predicament Kaufman discusses are far more severely limited in their capacities than someone such as my mother, and in their situation the line between “life” and “death” is indeed very ambiguous. By collapsing all such differences, however, and equating all forms of dementia with death, “horror stories” effectively pronounce a sentence of social death on anyone, whatever their degree of impairment, to whom that label has become affixed.

“Does she recognize you?”

When a person with dementia is narratively construed as “dead,” the main drama centers not on him or her but on the suffering of the spouse and family members. As Lawrence Cohen has noted, public discussions of Alzheimer’s describe it

as “a marathon,” an “exhausting vigil” given bodies “who need to be constantly watched or restrained,” an “ordeal” . . . and most tellingly, an “endless funeral.” . . . The suffering conveyed . . . by such temporal language is not that of the old person [but that of] “the other victims” . . . The continually reiterated discovery of Alzheimer’s journalism is that it is the caretaker who is the *real* victim. [Cohen 1998:54]

Caring for someone as dementia progresses and capacities recede is indeed an enormous job. I will be the first to point out that I am not the one who does most of the hard work of meeting my mother’s practical needs. Up until his death, my father was the one who took over all of the many tasks my mother used to do as, one by one and year by year, she lost the ability to manage them. By the time he died, he was doing all of the bills, all of the shopping, all of the cooking, all of the housework, as well as the yardwork, the laundry, the correspondence, and everything else that he had for most of a lifetime happily left to my mother (and before that, his mother). It’s possible, I think, that the strain of caring for her—or perhaps more accurately, the strain of caring for her while refusing all help and striving to “protect” her by concealing from others the extent of her impairment—may have been a factor contributing to the heart attack that killed him.

Today, three and a half years later, my Mom also needs help with toileting, showering, dressing, brushing teeth, going to bed, and must sometimes be reminded to eat. The vast bulk of this work is done by the kind, attentive, overburdened, and seriously underpaid workers—many of them first-generation immigrants from Somalia, Vietnam, the Philippines, and elsewhere—who staff the secure dementia ward of the upscale assisted-living facility where, thanks to a generous long-term-care insurance policy, my mother can afford to live. Even so, there remains plenty for my brothers and sister and me to do. My brothers and I take turns accompanying our Mom to checkups with doctors, dentists, ophthalmologists, and (more frequently than seems to me reasonable) nurses hired by the insurance company to conduct

“assessments” of her cognitive capacities. I shop for clothes or other items when Mom needs them, and talk with the staff at her facility about many small issues that arise from day to day. My sister manages our mother’s finances. The four of us e-mail each other regularly about this or that small issue that comes up. And of course, we visit her.

When people ask me whether my mother still “recognizes” me, they are expressing concern for me, asking me how I am bearing up under the burden of suffering that her dementia must place on me. When friends who have little experience of dementia sympathetically imagine what I must be going through, I suspect that they probably picture such day-to-day practicalities merging seamlessly with extreme emotional suffering, as part of “the horror of Alzheimer’s.” And they are quite ready to hear about my burdens and my suffering.

What they find much harder to hear, I think, is that I am *not* a victim, and being around my mother is *not* a nightmare or a horror. She is not “dead,” she is not “gone,” and she is not just a “body.” It is true that we have been very lucky: my mother’s decline has been very slow and gentle, and she has remained good tempered and affectionate throughout. I have never (yet) seen her become angry, suspicious, or violently agitated. She does not seem depressed. Aside from her dementia, my Mom is generally very healthy, remains physically mobile, suffers no chronic pain, and takes very little medication. Even though my Mom is seriously impaired she is still sweet, cheerful, and sociable. I enjoy her company. Many other families are far less fortunate in their experience of dementia, and for them perhaps the gothic and zombie stories do resonate. But my experience with my mother’s dementia is no “horror story”—and this, too, lies within the domain of the possible.

“Does she recognize you?”

“Recognition,” write the philosophers Nancy Fraser and Axel Honneth,

has become a keyword of our time. A venerable category of Hegelian philosophy, recently resuscitated by political theorists, this notion is proving central to efforts to conceptualize today’s struggles over identity and difference. Whether the issue is indigenous land claims or women’s carework, homosexual marriage or Muslim headscarves, moral philosophers increasingly use the term “recognition” to unpack the normative bases of political claims. They find that a category that conditions subjects’ autonomy on intersubjective regard well captures the moral stakes of many contemporary conflicts. [Fraser and Honneth 2003]

It was only after constantly being confronted with questions of “recognition,” that I became aware of philosophical writings on “the politics of recognition.” I turned to these works hoping to find there theoretical frameworks that would give me some critical purchase on the questions that have been bothering me: What social processes are at work behind this constant question about “recognition”? Why is it apparently so difficult for people to “recognize”—as a friend, as a person, as even being *alive*—someone who, because of dementia, can no longer keep names straight? How does the turning away of friends, at the level of personal networks,

relate to processes of “social death,” social exclusion, and abandonment of people with dementia on a broader level? In short, how do questions about “recognition” in its narrowly cognitive sense get implicated in the “politics of recognition” on a broader scale?

The philosopher Charles Taylor, in a landmark essay on “the politics of recognition,” contends that because a person’s sense of self is grounded in his or her membership in a cultural group, when the political system in which they live fails to recognize the cultural identity of the group to which they belong this causes real harm to individuals. As he writes, “Misrecognition shows not just a lack of due respect. It can inflict a grievous wound, saddling its victims with a crippling self-hatred” (Taylor 1994:26). This framework, developed in the context of engagement with debates concerning multiculturalism and identity politics, especially in North America, does not readily address the situation of people with dementia. Dementia sufferers do not constitute a cultural group in a way comparable to others that Taylor considers. Surely no one *develops* their primary sense of self centered on identification with dementia sufferers as a cultural group. Discourses that equate Alzheimer’s with death may indeed lead some people with dementia to suffer “crippling self-hatred,” especially now that the disease is often diagnosed early enough on that the affected person may be quite cognizant of the stigma attached to it. Yet political “misrecognition” such as Taylor describes is far from the only or primary challenge that dementia presents to the sense of self.

Nancy Fraser has developed a conception of “recognition” centered less on problems of the development of an individual’s sense of self, than on what she calls “the intersubjective condition of participatory parity” (Fraser 2003:36), in other words the “institutionalized patterns of cultural value” (Fraser 2003:37) that either allow or deny the people possibility of participating along with others on an equal footing, in a given activity or interaction. Fraser is concerned to develop an account of justice that can address, and distinguish among, the claims and demands made by various self-identified groups. Dementia Advocacy and Support Network International (DASNI), founded in 2001, is to the best of my knowledge the only identity-based group coalescing around the shared fact of having dementia. DASNI claims that roughly one-third of its members are people who have dementia themselves (DASN International 2008). DASNI’s leadership includes people with dementia, and one of the group’s primary aims is finding “ways the Alzheimer’s movement might become more inclusive of people with dementia” (DASN International 2008). One of the challenges that DASNI faces, however, is that people with dementia generally do not “identify” with their condition, nor claim common membership in a group of people with whom they share it. And, as Michael Bérubé points out, discussing “citizenship and disability” with reference to his son Jamie, who has Down’s syndrome:

Fraser writes as if the promise of democracy entails the promise to enhance participatory parity among citizens, which it does, and she writes as if we knew what “participatory parity” itself means, which we don’t. (Bérubé 2003)

It is not clear what forms of political participation lie within reach of people such as my mother, who (as documented by the “mini-mental status exam” that the

insurance company demanded) cannot say what day, month, season, or year it is, nor what city, state or country we are in. That the question is unclear does not mean that it is unimportant, nor need we necessarily jump to the conclusion that people with dementia *cannot* be more fully “recognized” as citizens, in terms of the “politics of recognition” as developed by Fraser, Taylor, and others. It does mean, however, that available theoretical frameworks fall short when they encounter dementia.

Developing philosophical arguments about “the politics of recognition” that might more easily accommodate the predicament of people with dementia will, I suspect, likely require looking for other ways of understanding “selves.” We may need to stop looking only to individuals as the bearers of “selfhood,” and start looking more at how “selfhood” is distributed among networks, sustained by supportive environments, emergent within practices of care. The critique that Ingunn Moser (N.d.) levels at a narrowly biomedical understanding of dementia is, I think, relevant also to political theory, to the extent that it too is premised on a rationalist and individualist understanding of the “self”:

Locating and fixing subjectivity and humanness in cognitive competencies and making autonomy and independence the gold standards for human subjectivity and agency, the biomedical version of dementia becomes fatal to the subject. [Moser N.d.]

To address how “recognition” in its narrowly cognitive sense gets implicated in the “politics of recognition” on a broader scale, arguments about the “politics of recognition” must be stretched to encompass what Annemarie Mol terms a “politics of what” (Mol 2003:177). “Recognition” is inseparable from “caring,” and both can be understood as not just the interior emotional or intellectual states of individuals, but as *practices*, particular forms of activity, at once social, representational, and very concretely material.

“Does she recognize you?”

My mother would certainly fail a pop quiz about my name, but she lights up when she sees me. She is eager to talk, and tries to speak, but words often elude her, and sentences get distracted and wander off in unanticipated directions. The difficulties of talking don’t seem to bother her terribly, though. There is pleasure in it still.

In a café, as we share a scone, Mom and I make what passes for conversation. I’ve learned to ask only the sort of question that does not require any specific information to answer: “So, things going okay with you these days?” “How’s my favorite Mom doing, you doing alright?” I tell her funny little stories about my kids. Sometimes we leaf through a magazine, looking at the pictures and commenting on them. Sometimes we look out the window, and I make general observations that require no specific response. “Looks like spring is coming, look at those leaves coming out on the trees.” “Sure are a lot of people out walking around today!” “That guy’s hair is really curly.” With each exchange Mom smiles at me, beaming affectionately in that familiar, slightly conspiratorial way, as if we are both in on the same joke.

And I begin to see, too, that Mom has her own experience of the world that is different from mine, and interesting in its own way. The loosening of memory that leaves her stranded in the present moment also allows her to inhabit it more fully than I am able to, caught up as I always am in the rush of my days, so full of schedules, deadlines, plans and arrangements. Morris Friedell, himself affected by Alzheimer's, describes how:

I find myself more visually sensitive . . . Everything seems richer: lines, planes, contrast. It is a wonderful compensation . . . We [who have Alzheimer's disease] can appreciate clouds, leaves, flowers as we never did before. [Shenk 2001:193]

Acknowledging this "compensation" is, in the words of Floyd Skloot (who writes beautifully about, and despite, his dementia),

not so much a matter of making lemonade out of life's lemons, but rather of learning to savor the shock, taste, texture and aftereffects of a mouthful of unadulterated citrus. [Skloot 2003:197]

As Mom and I walk slowly, hand in hand, around the neighborhood of the facility where she now lives, she responds with interest to so many things around us: the cuteness of a small child, the blueness of a blue house, the puzzling fact of an open car door, the surprise of a dog wearing a sweater, the improbable angle described by a man carrying a bag so heavy that he leans all to one side as he walks. Sometimes, in Mom's company, I am able to slow down enough to gain a new appreciation of the moment. A few days ago we spent a half hour looking out my mother's bedroom window to where a woman sat on the sidewalk outside, next to her baby in its stroller, blowing bubbles. The breeze caught the bubbles and carried them up, whirling and dancing, catching the afternoon light in brief rainbow flashes. It was the kind of thing I would not normally sit and watch—and it was beautiful. A young mother I do not know created a fleeting moment of wonder, and my own aging and impaired mother helped me to see it.

So. Our conversations go nowhere, but it hardly matters what we say, really, or whether we said it before, or whether it is accurate or interesting or even comprehensible. The exchange itself is the point. Mom and I are playing catch with expressions, including touches, smiles, and gestures as well as words, lobbing them back and forth to each other in slow easy underhand arcs. That she drops the ball more and more often doesn't stop the game from being enjoyable. It is a way of being together. Reflecting on his own mother's slide into dementia, the novelist Ian McEwan writes of her small comments and observations: "I understand her to be saying simply that she is very happy for us to be out together seeing the same things. The content is irrelevant. The business is sharing" (McEwan 2001).

Like many people whose knowledge of dementia comes primarily from the experience of caring for someone who has it, I came upon this perspective as if it were my own original discovery, not realizing until later that many scholars and researchers had already argued compellingly that, as Cohen puts it, "the senile deformation of meaningful utterance is not necessarily a turn to meaninglessness" (Cohen 2003:125).

It sounds crazy. It makes no sense if you pay attention to the words. But if you listen instead to the tone and the voice patterns, if you look at the body language, then it seems very much like a conversation. He asks. She answers. He comments. She comments. They take turns. They look at each other. Clearly they are connecting . . . We are so focused on words . . . on the act of talking, that we have forgotten how to communicate without them. More than that, we think there is no communication without words—which, of course, means that we believe we can't communicate with those who, in the later throes of Alzheimer's, have lost most of their language. These sentences Hayes and Frances M. say to each other may not make sense as conversation, yet there is meaning here . . . They are getting something out of this moment. [Kessler 2007:122]

Even when speech is incoherent and void of linguistic meaning, in face-to-face interaction there is a smooth and appropriate alternating pattern of vocalizing, as well as gesticulating, back and forth. With the utterance of only “Bah,” “Shah,” “Brrrr!” and “Bupalupah,” Abe and Anna were able to communicate without any recourse to intellectual interpretation. There was a fittingness and a meaningful relationship between the rise and fall of their pitch, their pauses, and their postural shifts. . . . What this example illustrates is Merleau-Ponty's argument that communication dwells in corporeality or, more specifically, in the body's capability to gesture. [Kontos 2006:207]

In the nursing home, a lot of residents had problems addressing one another or understanding what was being said. Yet the social convention of neighbour-talk about the weather was one they all understood. This enabled them to have conversations even with people suffering from aphasia who did not use words in a conventional way. The intonation was right for a chat about the weather, so the urgency to produce the right content was less. The transcript of such a conversation does not make sense at all, but in the specific situation the conversation can be smooth, pleasant and clear to everyone present. [Pols 2005:209]

There is, in short, much more to conversation than speech, and much more to speech than the transmittal of information. It is a commonplace of scientific research into Alzheimer's and other forms of dementia that procedural memory (knowing *how to do* such-and-such) often persists much longer than propositional memory (knowing *that* such-and-such). People who are no longer able to speak coherently may often still take part in, and enjoy, activities such as walking, dancing, or singing that rely on embodied procedural memory.

Conversation itself is, for my mother, one of these activities. So much of it really is procedural, a knowing *how to* interact with people. When I make a joke, she laughs. When I tell some small story about something that happened, she murmurs sympathetically. When I express an opinion, she agrees. When we sit together, she attends to my presence, reaches out to me, pats my hand. These communicative practices are, I believe, also practices of *caring*—my mother *cares about* smoothness of the back-and-forth flow, *takes care* to keep it all going, and in doing so she acts in a *caring* way toward me and other people around her.

“Does she recognize you?”

She may not “recognize” me in a narrowly cognitive sense, but my Mom does “recognize” me as someone who is there with her, someone familiar perhaps, and she does not need to have all the details sorted out in order to “care” for me. The impulse to care, the habit of caring, the embodied knowledge of how to take care—these things run deep in my mother, a good woman according to the norms of her generation, who for most of her life was very engaged in caring for other people: her children, her husband, her grandchildren, her friends. Not long ago, when I arrived to visit Mom, I found her sitting in the activity room holding in her lap, with practiced ease, a very realistic baby doll dressed in a purple outfit. Seeing me, she smiled, and beamed down at the doll. “Look at him! So cute!” She shifted him gently in her arm, fussed a little with his outfit, and looked up at me again. “I don’t think he’s going to wake up.” The fact that my mother was holding a doll, and that she likely could not clearly distinguish it from a real live baby is, to me, less important than the revelation that this moment offered, of the persistence within her of the procedural knowledge of how to care, and the desire and need to do so. The progress of her dementia makes it difficult for Mom, now, to comprehend the nature of other people’s needs or the sources of their suffering, but she still does notice and respond to others, and is still moved to try to alleviate their distress.

Sometimes, this disjunct between a severely diminished capacity to comprehend and an undimmed capacity to care can lead to painfully ironic situations. On the day that my father died, my brothers and sister and I gathered at our parents’ house, stunned, trying to comprehend what had happened and what we must do next, drinking the still-warm coffee that Dad had brewed that morning, and weeping. Although we had explained it to her, Mom did not grasp that her husband of forty-nine years was gone. At one point, she looked at my younger brother and noticed that his eyes were all red and swollen. Reaching out to caress his arm, her face drawn into an expression of sympathetic concern, she looked up at him and asked, tenderly, “What’s wrong? Do you have a cold?”

But sometimes, when distress is simpler and its sources less dramatic, such caring alone is a precious gift. One time, a little more than a year ago, I stopped by the assisted-living facility where my mother was living at the end of a very busy day in an especially hectic week—I had stayed up very late the night before trying to finish grading student papers, then spent the whole day teaching and in meetings. I found her sitting in a common area, and went with her up to her room. I turned on the TV and we sat down together on the couch. Exhausted, I leaned back and yawned. Mom patted my hand, and said to me, “You’re tired! Just go ahead and sleep! You can just lay down right here.” And so I sat there next to my Mom, holding her hand, feeling her warmth against me all along one side of my body, and I leaned my head on her shoulder, and slept. When I awoke twenty minutes or so later, I felt better—a little bit rested, and deeply comforted by the fact that the mother I now take care of can still, in some small but important ways, also take care of me.

Even some of the odd behavioral quirks that my Mom has developed make sense to me in these terms, as expressions of care couched in the idiom of dementia. People with dementia often develop strong impulses to engage in particular forms of repetitive behaviors, and Mom is no exception. When I take her out to a café, I

usually get a cup of black coffee for myself, and order a cup of hot chocolate for her (not *too* hot, and don't forget the whipped cream on top!). As we drink them, she checks constantly to see whether my cup and hers are "even," whether the liquids have been drunk down to the same level. If not, she will hurry up and drink more to "catch up," or else stop and wait for me. If we share a cookie, she is concerned to make sure that the halves be the same size, and that we eat them at the same rate. Cookies also leave crumbs, of course, and those disturb her—surfaces should be smooth and clean. She will wipe all the crumbs off the table and onto a napkin, then carefully fold up the napkin with the crumbs inside. Or she will take another napkin and wipe away at the inside of her cup, where the receding hot chocolate has left a little residue of foam and whipped cream. Then she will carefully pile up the hot-chocolate napkin, the cookie-crumbs napkin, and any other napkins on the table, along with any other papers within easy reach, into a neat and symmetrical stack. She likes to secure such piles, when she can, by wrapping them up with rubber bands, or clipping them together, or putting them inside a plastic Ziploc bag or envelope or into her pocket. Given the opportunity and the materials, she tends to prefer to wrap, clip, *and* enclose. When my siblings and I sorted through our parents' forty years of accumulated stuff, clearing out their house so that it could be sold, we found among Mom's things (with a mixture of hilarity and dismay) many strange little bundles, odds and ends multiply wrapped and rubber banded and clipped together.

Such behaviors are a little weird, to be sure. It is the sort of thing that makes people uncomfortable. Other people in the café give us odd looks when Mom starts in on her wiping and folding. The other residents at the place she used to live, most of whom were not impaired themselves, did not much like it when she began collecting their mail out of their cubbies and "organizing" it into piles. The nurse there regarded Mom's pile making as a symptom of "obsessive-compulsive disorder" and suggested to me that we start her on Prozac. (I refused.)

I think it is also possible, however, to read such behaviors as, at least in part, expressions of *care*. Explaining her use of the phrase "logic of care," Annemarie Mol explains that she:

seeks a local, fragile, and yet pertinent coherence. This coherence is not necessarily obvious to the people involved. It need not even be verbally available to them. It may be implicit: embedded in practices, buildings, habits, and machines. And yet, if we want to talk about it we need to translate a logic into language. This, then, is what I am after. I will make words for, and out of, practices. [Mol 2008:8]

Ingunn Moser (N.d.) and Jeanette Pols (2005) document how a "logic of care" is implicit within practices of dementia nursing care. Such a logic may be present also within the practices of people with dementia themselves. Keeping track of whether our drinks and cookies are "even" comes naturally to a woman who has always had to carefully divide quite limited resources, first with her own brothers, and later among her four children. When she starts in on her work of wiping crumbs and clipping together papers, her hands are well practiced in such motions from the years that she spent cleaning the kitchen counters, picking up after me and my siblings, working to create an orderly home. She has cared about such details all

her life—and caring about them, taking care of them, was also a way in which she cared for other people. My mother has always worked to impose on the resistant matter of her world an order, at once aesthetic and moral, of evenness, fairness, smoothness, and security. Dementia has made such efforts far more difficult, but they deserve nonetheless to be “recognized.”

“Does she recognize you?”

Two and a half years ago now, ten months after my father’s death, I arrived at my Mom’s apartment one day and found her sitting on her couch, busily going through some papers. “These are for my Dad,” she explained.

I sat down next to her, to join in with her in her task. She was taking pieces of paper out of her purse, which was crammed to bursting with them, looking at each one, and then putting them into a pile next to her. I took this pile onto my lap and looked through it. It contained a very random assortment of things: blank sheets of stationery decorated with a floral design, condolence cards that friends had sent to her, subscription-reply cards from magazines, sections of months-old newspapers, napkins. And on top of these, there was a very old airmail envelope, yellowing and brittle, with a letter inside.

I took the letter out and opened it up. Dated April 7, 1968, it was written in my maternal grandfather’s spidery handwriting. “Dear Aunt Pearl,” he wrote. “Now. Please do not faint, but after reading your letter that you sent Ruth last February and she sent on to me, I just had to write and thank you for your kind cooperation. My oldest Boy ‘Bill’ has the Idea that he wants to know more about the family. Your letter, which I forwarded to him to-day, should be a great help.” He went on to reminisce fondly about visiting with her and her family in 1931, and sent news of his daughter and two sons, including the names and ages of my mother’s four small children. “Thank you again for your cooperation,” he ended, “and now that I relize I can write, I just may drop you another line.”

To come across a letter you have never seen before, written by a person you loved who died many years ago, can be a moving experience—perhaps especially when the letter is one of very few artifacts left behind at the end of a humble life such as my Grandpa lived. And I was touched to see that my uncle Bill, also dead now, who in 1996 self-published a book-length family history of which he was very proud, had already begun work on this project thirty years earlier, when still a quite young man.

What staggered me, though, was what I saw written in the blank space at the top of the letter, in my mother’s handwriting:

Licends—Please try to keep cares together!

We will try to keep Diana, Janelle, Mike and Pat. Will try to keep the cares together.

I cannot know exactly when my mother wrote this, but it is clear—from the oddness of the spelling and phrasing, as well as the shakiness of her handwriting—that she was already quite far along her path of progressive dementia.

It is tempting to grasp onto these words as representing a coherent and stable, if hidden, “perspective” on the world, but I know that that would be a mistake (Pols 2005). Mom can no longer write. If I were to show her this note today, she would probably not be able to read it, nor would she recognize the words as her own. This note is nothing more, and nothing less, than a small fragment of wisdom, the material trace of one moment in her mighty effort to resist her losses. At some point—struggling to write, struggling to order her thoughts and her life—my mother named us, her children, as “the cares,” and exhorted herself to “try to keep the cares together!” and promised to do so. The slip of paper on which she chose to write this note to herself was a letter from her much-loved and long-lost father, to a relative he had not seen for many years, thanking her for helping his son try to document their family history. Generation upon generation, writing upon writing, layer upon layer of struggles, across the years, to “keep the cares together.” With this essay, I suppose, I add yet another layer of my own.

“Does she recognize you?”

For a while, after we first moved my mother into an assisted-living facility, she often said that she wanted to “go home.” I understood this to mean that she wanted to move back to the house where she had lived for forty years until my father’s death, the house in which I grew up. Usually, I responded with my own mild version of “reality orientation,” explaining, as gently as possible, that that house was all empty and cold now, and nobody was there to keep her company or help her do stuff, so it was probably better to stay here.

One time, though, I asked her a question instead. “You mean home to the house up in Edmonds?”

“No, on the farm,” she answered. “You go down. . . .” With her raised arm, she traced out the curve of a long-ago road. For the first seven years of her life, my mother had lived on a small farm in southern Idaho, before her father moved the family to Seattle during WWII to seek work on the docks.

“They’re inside there,” she added.

“Who?” I asked.

“My Mom and my Dad.”

My mother is a woman in her seventies. Her parents are not waiting for her inside an Idaho farmhouse. Taken one way, a moment such as this gives clear evidence of my mother’s inability to “recognize” people and things around her. You could use that evidence to draw a clear line between us: place me here, on the side of reality, competence, and personhood, and put her over there, on the side of delusion, incapacity, and the not quite (or no longer) fully human.

What I took from that moment, however, was something different. I realized that what she was longing for was not *my* childhood home, but *hers*. She missed her Mom and Dad. She was trying, in her own way, to hold on to them—just as I was trying, against the odds, to hold on to her. Our predicament is exactly the same.

The ravages of time, aging, and disease mean that my mother’s efforts to “keep the cares together” are ultimately doomed to fail. In that respect, however, she is

hardly alone. Everyone becomes impaired in one way or another, unless we die first. Every human being begins life utterly reliant on kindnesses he can neither remember nor repay, and many of us will end our lives in a similar state. As *individuals*, every one of us is bound to fail to keep the cares together. It is only as members of communities that any of us can hope to transcend forgetfulness and death.

Why then should a person be cast out and abandoned, condemned to social death, and denied recognition as a friend, a person, a fellow human being, just because she shows signs of succumbing to the same forces that we know will eventually claim each one of us? Can we not resist this “erosion of personhood” (Luborsky 1994), and “overcome the notion that cognition is the decisive carrier of personhood” (Leibing 2006:258)? Rather than make an individual’s claim to social and political “recognition” contingent on the narrowly cognitive ability to “recognize” people, words, and things, we would do well to emulate this humble, ailing individual woman’s effort to hold fast to “the cares”—what she has cared about, who she has cared for and taken care of. Let us strive to hold on to “care” as something that makes life worthwhile.

“Does she recognize you?”

I wish that just once, someone would ask me a different question.

I can picture it very clearly. This is how it will happen. I will run into a friend, or coworker, or acquaintance, or neighbor, or one of my mother’s old friends. We will chat about this and that. I will mention my mother, and her dementia. This person will look into my eyes and ask me:

“Janelle, are you keeping the cares together?”

“I’m doing my best,” I will answer.

“ . . . And you?”

Note

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References Cited

- Bérubé, M.
2003 Citizenship and Disability. *Dissent* 50(2):52–58.

- Cohen, L.
 1998 *No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things*. Berkeley: University of California Press.
 2003 *Senility and Irony's Age*. In *Illness and Irony: On the Ambiguity of Suffering in Culture*. M. Lambek and P. Antze, eds. New York: Berghahn.
- Connolly, J.
 2007 *Charting a Course for Recognition: A Review Essay*. *History of the Human Sciences* 20:133–144.
- Cooney, E.
 2001 *Death in Slow Motion: A Descent into Alzheimer's*. *Harper's* (October): 43–58.
 DASN International
 2008 Home Page. Electronic document, <http://www.dasninternational.org/index.php>, accessed April 30, 2008.
- Fraser, N.
 2003 *Social Justice in the Age of Identity Politics: Redistribution, Recognition, and Participation*. In *Redistribution or Recognition? A Political–Philosophical Exchange*. N. Fraser and A. Honneth, eds. Pp. 7–109. London: Verso.
- Fraser, N., and A. Honneth
 2003 *Introduction: Redistribution or Recognition?* In *Redistribution or Recognition? A Political–Philosophical Exchange*. N. Fraser and A. Honneth, eds. Pp. 1–6. London: Verso.
- Friedell, M.
 2003 *Tedious No More!* Electronic document, <http://members.aol.com/MorrisFF/Tedious.html>, accessed April 29, 2008.
- Fuchs, E.
 2005 *Making an Exit: A Mother–Daughter Drama with Alzheimer's, Machine Tools, and Laughter*. New York: Holt.
- Goffman, E.
 1961 *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Doubleday.
- Greater Dallas Chapter
 2007 Home Page. Electronic document, <http://www.alz.org/greaterdallas/>, accessed September 1, 2007.
- Henderson, J. N.
 2003 *Alzheimer's Units and Special Care: A Soteriological Fantasy*. In *Gray Areas: Ethnographic Encounters with Nursing Home Culture*. P. B. Stafford, ed. Pp. 153–172. Santa Fe, NM: School of American Research Press.
- Holden, S.
 2002 *When Love and Disease Both Strike Out of the Blue*. Review of Bille August's film *A Song for Martin*, 2001.
- Kaufman, S.
 2005 *Dementia-Near-Death and "Life Itself."* In *Thinking about Dementia: Culture, Loss, and the Anthropology of Senility*. A. Leibing and L. Cohen, eds. Pp. 23–42. New Brunswick, NJ: Rutgers University Press.
- Kessler, L.
 2007 *Dancing with Rose: Finding Life in the Land of Alzheimer's*. New York: Viking.
- Kontos, P.
 2006 *Embodied Selfhood: An Ethnographic Exploration of Alzheimer's Disease*. In *Thinking about Dementia: Culture, Loss, and the Anthropology of Senility*. A. Leibing and L. Cohen, eds. Pp. 195–217. New Brunswick, NJ: Rutgers University Press.

- Leibing, A.
2006 Divided Gazes: Alzheimer's Disease, the Person within, and Death in Life. *In* Thinking about Dementia: Culture, Loss, and the Anthropology of Senility. A. Leibing and L. Cohen, eds. Pp. 240–268. New Brunswick, NJ: Rutgers University Press.
- Luborsky, M. R.
1994 The Cultural Adversity of Physical Disability: Erosion of Full Adult Personhood. *Journal of Aging Studies* 8(3):239–253.
- Margalit, A.
2002 *The Ethics of Memory*. Cambridge, MA: Harvard University Press.
- McEwan, I.
2001 Mother Tongue. Electronic document, <http://www.ianmcewan.com/bib/articles/mother-tongue.html>, accessed September 9, 2008.
- Mol, A.
2003 *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.
2008 *The Logic of Care: Health and the Problem of Patient Choice*. New York: Routledge.
- Moser, I.
N.d. Should We Hope for a World without Alzheimer's? *Re/Articulating Subjectivity and Humanness in Biomedicine, Dementia Care, and STS*. Unpublished manuscript.
- Plath, D. W.
1980 *Long Engagements: Maturity in Modern Japan*. Stanford, CA: Stanford University Press.
- Pols, J.
2005 Enacting Appreciations: Beyond the Patient Perspective. *Health Care Analysis* 13(3):203–221.
- Ricoeur, P.
2005 *The Course of Recognition*. Cambridge, MA: Harvard University Press.
- Shenk, D.
2001 *The Forgetting: Alzheimer's, Portrait of an Epidemic*. New York: Random House.
- Skloot, F.
2003 *In the Shadow of Memory*. Lincoln: University of Nebraska Press.
- Strauss, C. J.
2001 Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend. Oakland, CA: New Harbinger Press.
- Sweeting, H., and M. Gilhooly
1997 Dementia and the Phenomenon of Social Death. *Sociology of Health and Illness* 19(1):93–117.
- Taylor, C.
1994 The Politics of Recognition. *In* *Multiculturalism: Examining the Politics of Recognition*. Amy Gutman, ed. Pp. 25–73. Princeton: Princeton University Press.
- Yamamoto-Mitani, N., C. S. Aneshensel, and L. Levy-Storms
2002 Patterns of Family Visiting with Institutionalized Elders: The Case of Dementia. *Journal of Gerontology: Social Sciences* 57B(4):S234–S246.