

Hilde Lindemann, "On the Mend: Alzheimer's and Family Caregiving," *The Journal of Clinical Ethics* 16, no. 4 (Winter 2005): 314-20.

On the Mend: Alzheimer's and Family Caregiving

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As she let me into the kitchen I've known all my life, her eyes were too bright — as if at any moment they might spill over with excitement or anger or some third uneasy thing. I set the groceries down on the counter and took off my coat, watching her warily as she put the food away. She doesn't let me help with this because she wants to show me that she can still do it by herself, I suppose, so I sat down at the table and told her that Ellen sent her love.

"Ellen?" She trotted quickly from cupboard to counter to refrigerator, not with the old competence but forcefully, as if propelled.

"Your granddaughter, Mama. She would have come with me tonight but she's studying for a history test. It's the first free evening she's had all —"

"I know who you're talking about and I don't want her coming around here anymore," she interrupted. "She's a thief, that one. She steals from me. First she stole my —" she stopped, groping for the word "— my silver engine starter." She looked puzzled, but ploughed on, "And then she stole my car, but she won't get any of my money, that's for sure. That's hidden someplace where she'll never find it."

I took a deep breath. "Oh Mama, Ellen didn't steal your car. We sold it for you last month, after the doctor told you it wasn't safe for you to drive anymore. Don't you remember?"

She shut the refrigerator door and turned to face me, moving crabwise to the nearest chair as if she needed to keep the table between us. "What did you do with the money?" she demanded.

"It's in the bank." I tried to keep the patience out of my voice. "You got in my car and we drove to the bank, and you deposited it in your checking account. Really you did."

She sat down, her back stiff and her mouth a thin tight line. It was a look I had seen sometimes in childhood, when she fought with my father about money. Their fights terrified my brother and me, possibly because they happened so seldom. We would sit at this table, the gravy congealing on our plates, while he raged at her for her miserliness and she drew herself up into a figure of imperious resistance. At those moments we children got a glimpse of something hard inside her that was usually buried deep under many layers of softness. A splinter of cruelty that her disintegrating self could no longer conceal.

"Mama," I said desperately, "have you had your supper yet?" I'd tried diversionary tactics before and they sometimes worked. They worked now. She'd been waiting for the groceries, she said, and yes, an omelet would be nice. I sautéed onions and mushrooms, made tea, buttered toast, threw a handful of Swiss cheese on top of the half-set eggs, added the sauté, and folded the omelet. As I cooked, I jollied her. "What does the Perfect Housewife do when supper's late?"

She grinned. "Fry an onion!"

"So your hungry family knows that help is on the way," I finished. "Best piece of advice you ever gave me."

"That, and 'Never marry on the rebound'," she agreed. The kitchen returned to normal. I brought her food to the table and poured tea for myself in the special blue mug I'd been drinking from since I was nine. As she ate, we talked of her own mother and dad, and her childhood in German-speaking Milwaukee. She liked that topic because she could remember it, and remembering made her feel safe. We lingered over her meal, me playing the straight man and she preening, and both of us content.

Finally I rose from the table and began to clear away the dishes. "It's getting late," I said. "I'll look in on you tomorrow — maybe around six?"

"Six is fine."

"Okay then, sleep tight." I put on my coat and kissed her, and then I remembered her meds. "I almost forgot your pills. Stay put — I'll get them."

I went into her bedroom, switched on the lamp on her nightstand, and opened the drawer. As I slid my hand inside, I felt a hot rake of pain. I could smell the blood before I could see it, and I pulled the drawer wide before I carefully extracted my hand. Blood was everywhere, flowing freely from the four long gashes on the top of my hand, oozing and sticking around my palm, falling in great drops onto the wooden bottom of the drawer. Bending down, I could see the old-fashioned razor blades that had been stuck with some kind of caulk to the top of the frame. I straightened up, looking for something to stanch the bleeding, and saw my mother standing in the doorway.

"That's what happens to thieves," she spat. She had drawn herself up to full majesty, and she was shaking with fury. "Thief! Robber! Get out of my house before I call the cops on you!"

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There are currently 4 million people in the United States who suffer from Alzheimer's or some other progressive dementia; the Alzheimer's Association estimates that this number will increase to 14 million by 2050 unless a cure is found. At present, of course, there is no cure. Those who are afflicted will surely and inexorably lose their memories, their speech, and then all their capabilities. In the end, the disease will kill them unless a more merciful death intervenes.

There is no restitution narrative to be told for Alzheimer's — no story of health, then illness, then illness overcome. But because any serious disease attacks the person and not just the body, and because progressively dementing diseases are particularly efficient in this respect, we may speak here of a certain kind of *moral* mending and of the narratives that are needed to bring it about.

In this article I invite you to consider with me just exactly what this moral mending amounts to. Using my opening story as a case in point, I'm going to try to accomplish three things. First, I'll motivate the thought that the daughter in the story has a duty to hold her mother in personhood — and I'll explain what I mean by that phrase. Second, I'll argue that one thing preventing the daughter from holding her mother in personhood as well as she should is a story that collaborates with the Alzheimer's disease in damaging her mother's identity. Third, I'll sketch out a counterstory that could repair the mother's identity and so mend the injury to her personhood.

HOLDING SOMEONE IN PERSONHOOD

Implicit in the notion of personhood is the complicated set of reactions and attitudes that both express and sustain what is fundamentally a particular kind of moral relationship. To elucidate this relationship, I begin with Wittgenstein's observation in the *Philosophical Investigations* that "the human body is the best picture of the human soul."¹ All of the section containing this remark deals with how we recognize and respond to people's so-called psychological or mental states — what we tend to think of as people's inner lives. It's by paying attention to their bodily postures, gestures, and expressions that we can tell whether they

are excited, puzzled, or interested; whether they are praying, fearing, or intending. And it's our ability to read these states off human bodies that allows us to see human beings as personalities rather than as furniture, plants, or pets. The capacity to generate selected items in the changing procession of sensations, emotions, beliefs, attitudes, wishes, misgivings, and other mental states that cross a human consciousness has been taken by some philosophers to be either necessary or sufficient for personhood, but if we take seriously that these states are socially mediated and that persons too are essentially social, then, rather than tying personhood solely to capabilities and competencies residing within the individual, we have to see it as partly also an interpersonal achievement.

The construction and maintenance of a personal identity is an integral part of this achievement. I have argued elsewhere that identities, in the sense of how we see ourselves and who other people understand us to be, are narratively constituted. They consist of tissues of stories and fragments of stories, generated from both first- and third-person perspectives, that cluster around what we take to be our own or others' most important acts, experiences, characteristics, roles, relationships, and commitments. In short, they are narrative understandings formed out of the interaction between one's self-concept and others' sense of who one is.²

Many of the narrative understandings forming a part of a personal identity draw on stock plots and character types that are familiar to us all: Cinderella, the whore with a heart of gold, and the Good Samaritan, for example, are characters whose stories we know so well that we readily use them to make sense of actual people. Socially shared narratives contribute to the identities of groups as well as individuals, and members of the group draw a part of their identity from how the group identity is narratively constructed.

Other parts of the narrative tissue that constitute a personal identity consist of the localized, particular stories that pick an individual out as distinct from others in the groups to which she belongs: these are the stories that distinguish this mother from the other members of her family, or from the class of people with Alzheimer's disease. They are the stories of the mother's childhood in a German-speaking immigrant family, of her college days during the Second World War, of her marriage to a man who was 15 years her senior, of her living children and the daughter who died in infancy, of her years as a high school teacher, her widowhood, her retirement. And among them is the story of the evening I just recounted, when the mother hurt her daughter's hand.

Personal identities function as counters in our social transactions, in that they convey understandings of what those who bear them are expected to do. If an answer to Who are you? is "the bartender," for example, I expect you to know how to mix a martini; if the answer is "a practicing Muslim," I don't. Moreover, identities also stand surrogate for how those who bear them may be treated. If you're my three-year-old son, I can remind you to use the toilet, but if you're my dean, I'd better not. Personal identities make intelligible to us, then, not only how other people are supposed to act, but how *we* are supposed to act with respect to them. And because stories depict time passing, the narratives that constitute identities can reflect the respects in which we change, as well as how we remain the same.

Pushing Wittgenstein's "picture" remark one step further, I propose that (1) our socially mediated psychological states, (2) their bodily expressions, (3) others' recognition of these expressions, and (4) the treatment based on that recognition all play a part in the formation and maintenance of the relationship called personhood. Indeed, I argue that personhood just *is* the expression on a human body of the socially mediated feelings, thoughts, desires, and intentions that constitute a human personality, as recognized by at least some others, who then respond in certain ways to what they see. *Recognition* includes establishing a personal identity by engaging in the narrative activity that constitutes our sense of who the person is. *Response* includes the attitudes and actions we take toward the person — what we do to or for the person and what we expect from the person — on the basis of that identity-constituting, narrative activity. The bodily depiction of the succession of mental states and the uptake of that depiction by others in the form of recognition and response make up the social practice of personhood, the practice on which all other social practices rest.

The ability to participate in this practice can be blocked when any of its four components fail to function normally. There are, speaking very generally, two sorts of causes for these components' failure to function.

The first is natural contingency. Mental retardation, progressive dementia, and mental illness, for example, can diminish or fragment the thoughts, feelings, and attitudes that find bodily expression. Paraplegia, muscular dystrophy, and amyotrophic lateral sclerosis immobilize the body, so that even if the individual can form sound beliefs, intentions, and so on, their expression is relatively difficult.

The second cause of the components' failure to function is human agency. The features of a human personality can be shattered by traumatic brain injury, whether accidentally inflicted or deliberately engineered. Bodies can be immobilized in ways that precludes the expression of attitudes or ideas, by maiming the bodies or keeping them in solitary confinement.

With respect to bodies and what Wittgenstein calls souls, then, human agency and natural contingency are equally capable of wreaking the kind of havoc that keeps a human being from participating in the ordinary practice of personhood. But where human agency has the advantage over nature is that it can also sabotage recognition and respect, the other two components of the practice. By refusing to recognize that certain human beings are actually expressing the thoughts, temperament, and so on that constitute a personality, powerful persons can consign them to the status of nonpersons, thereby blocking their participation in the practice of personhood. And finally, by ignoring or covering up expressions that are properly recognized, persons can refuse to respond to others, and once again their participation in the practice of personhood is blocked.

The practice of personhood, which is unreflective, reciprocal, and as common as breathing, can be distinguished from the practice of *holding* someone in personhood, which is often equally unreflective, but one-sided, and far less common. It is done by recognizing and responding to someone who cannot, for one of the aforementioned kinds of reasons, engage in practices of personhood herself. When a person with Alzheimer's is cared for at home, for example, family members may maintain her personal identity for her. As she loses her ability to contribute first-person stories to the tissue of narratives that constitute her identity, her caregivers and other intimates can persist in the third-person narrative activity that has already constituted their sense of who she is. They can continue to combine the plot templates and personae of widely known and socially shared narratives with their own, more local stories of who she is, and then treat her according to the narrative understanding they have created for her. In this way they hold her in personhood, even though she can contribute very little to the practice herself.

Now let's return to the story of the mother and daughter with which I began. Does the daughter have a duty to hold her demented mother in personhood? Holding someone in personhood keeps the individual within the special place reserved for persons inside the moral community. To fall outside that place in the community is to lose one's claim to a particular kind of moral consideration, and that is a serious harm. Personhood is, I repeat, at bottom a moral relationship. As such, it commands the particular moral consideration that Kant called respect and the high moral valuation that he called dignity.

This mother *is* a person. But she is having serious trouble maintaining her personhood, and is losing her ability to recognize and appropriately respond to those who care for her. Given how eggshell-thin the protection can be that stands between any one of us and the exile from humanity that is the essence of Alzheimer's, I believe we must all take responsibility for holding in personhood those who fall prey to this disease. And because the mother-daughter relationship is one that ordinarily gives rise to special responsibilities, the mother's moral vulnerability exerts a particularly strong pull on her daughter.

NARRATIVE COMPLICITY

A crucial part of what's involved in holding someone in personhood is the narrative activity of maintaining the person's identity, as the stories that constitute our sense of who the person is are the ones that guide our treatment of her. If, for example, I draw on the stock character of the gay man as child molester that has circulated widely through our culture since the late 1930s,³ and I learn that my child's kindergarten teacher is gay, my response to him may well be a mixture of fear and loathing, and I am likely to treat him with contempt, if not worse. It matters very much *which* stories contribute to a person's identity, and we are

morally responsible for the ones we endorse. The story of the gay child molester damages this teacher's identity. It's not only a dignitary offense and a slur on his reputation — it could cost him his job and maybe even his life.

I want to suggest that the daughter in my opening story has endorsed a narrative that damages her mother's identity. Like the child molester narrative, the story in question is widely shared and socially circulated. Unlike the child molester narrative, though, the story the daughter has incorporated into her mother's identity has a surface plausibility that makes it appear innocent and harmless. It's the story of the "real self."

Recall that when the mother accuses the granddaughter of having stolen her car and demands to know what happened to the money, the daughter's tale goes like this:

We would sit at this table, the gravy congealing on our plates, while he raged at her for her miserliness and she drew herself up into a figure of imperious resistance. At those moments we children got a glimpse of something hard inside her that was usually buried deep under many layers of softness. A splinter of cruelty that her disintegrating self could no longer conceal.

The daughter's presupposition of her mother's real self lies in the notion of a splinter of cruelty where the mother's heart should be — a splinter buried deep under many layers of maternal warmth, love, and kindness. All those layers of softness, the daughter seems to think, are just a civilized outer wrapping. Now that Alzheimer's has rotted the wrapping so that long strips of it have begun to fall away, the daughter can see who her mother really is.

But does the term "real self" refer to anything actual? If, as I have argued, personal identities are narrative understanding of selves as they change over time, then a claim to know someone's real self presupposes something about what the identity represents or how it represents it. I can think of three possibilities here. First, the claim might be less about the self than about the identity: a "real self" might be the one that a defective set of stories failed to capture. That the stories constituting an identity could misrepresent the person is certainly a possibility, but that doesn't seem to be what people mean when they say that they have finally discovered who someone really was — they seem to mean that they've discerned some core or inner self they hadn't seen before.

This suggests a second possibility, namely, that the reference is to a self that is credibly depicted by the narratives that constituted the person's identity *at a certain time*, which was then covered up by later accretions and is now uncovered again as a result of progressive dementia. But then we need to explain why that earlier point in time carries more narrative weight than any other, and how we can know that dementia has uncovered it. Is the thought here that Alzheimer's has loosened the inhibitions that formerly kept the authentic self in check? And are we privileging the self that is now uncovered because it's what is left at the end of the actions and choices the person has been responsible for in the course of her life? While it's true that some judgments about someone's life can only be made after one knows how various choices, deeds, or guesses ultimately turned out, there's no good reason to suppose that the knowledge of how things turned out must coincide precisely with the final years of the person's active biography. The consequences of some choices will be apparent much earlier; the ramifications of others may continue long after the person is dead. It is worth bearing in mind that the decline into dementia offers no more of a God's-eye view from which to judge a life than any other location; it too is a particular context with its own limited sight-lines.

That leaves a third possibility, which is that the reference is to an aspect of the self depicted by a particular *story line* that runs throughout a person's life, rather than attaching to a specific point in time. Does the daughter suppose that the narrative that binds together all of the episodes of avarice in her mother's life is the one that shows her as she really is? In that case, we need to explain why *that* story depicts something more real than the other stories that constitute the identity. Was she often avaricious? Apparently not, or her children wouldn't remark on how seldom these episodes took place. Was she deeply cruel on the few occasions when avarice entered the picture at all? We have no reason to think so. In the absence of something that

explains why we should give extra narrative weight to either an earlier point in the mother's life or a particular story line that runs throughout it, it's hard to see how one part of her self could be more real than all the others.

In a recent essay in the *Hastings Center Report*,⁴ the philosopher and neurosurgeon Grant Gillett rejects the familiar conception of the self and mind, whereby the higher brain keeps a tight rein on the hidden snakepit of wayward impulses that constitutes our real selves. This picture, promulgated in various guises by Freud, Darwin, and Jaspers, has been called into question not only by Wittgenstein, but a number of others who have proposed instead that conscious thought is the product of socialization and training within a given form of life. "It is only as we engage in the everyday forms of life, those communal patterns of behavior where we learn to think and talk about things, that the contents of the mind take on a determinate shape," says Gillett.⁵ We live out our lives in this interaction between mind and world, participating in the discursive activity that forms us as persons and then shaping our experiences through the choices we make and the interpretations available to us in the social locations we inhabit. Gillett likens the shaping of a human self to the weaving of a tapestry. And he insists that it would be as mistaken to say that the real self is the one degraded by Alzheimer's as to say that the real tapestry is the "mish-mash of disordered threads and fragments of intact weaving"⁶ left after the moths have gotten at it.

I believe Gillett is quite right about this, and that the narrative of the "real self" is pernicious. If the daughter in my story were actively to endorse it (rather than tacitly presupposing it, which is all she's done with it at this point), she would, I submit, do serious damage to her mother's identity. And she would be damaging it at a time when it's already heavily under siege. One of the most devastating effects of Alzheimer's is to disorder the mental processes that are most intimately bound up with the self, at the same time as it robs people of the words that give the self much of its physical expression. Increasingly, the disease will disable the mother's capacity to contribute first-person stories to the narrative tissue that is her identity; increasingly, the task of identity maintenance will fall on those who care for her. If the daughter now characterizes her mother as essentially flint-hearted, she collaborates with the disease in the damage it inflicts.

And this in turn makes it harder for the daughter to hold her mother in personhood. Recall that I analyzed the practice of personhood into four components: our socially mediated psychological states, their physical depictions, others' recognition of these depictions, and the treatment based on that recognition. Alzheimer's has begun to fracture the mother's psychological states and has driven her to physical expressions — the razors in the drawer — that are appallingly off-kilter. Two of the four components of personhood are therefore already malfunctioning. Should the daughter fail to *recognize* who her mother is because she employs a faulty identity-constituting story, the third component misfires as well. And if she *responds* to her mother on the basis of that faulty story, she has nothing left with which to hold her mother in personhood.

THE COUNTERSTORY

The daughter needs a counterstory — an identity-constituting story that resists the ravages of her mother's disease and reidentifies her mother as a morally valuable person. The story should be true, as mending an identity requires *accuracy*: the story must be a faithful likeness. But faithful to what? To the woman standing in the doorway in triumph as her daughter bleeds copiously into the drawer? No, for that isn't a story — it's just a snapshot of a particularly awful moment in this woman's life. A *story* depicts that life over time, selecting characteristic episodes, interpreting the life through what it selects, and connecting itself to a vast web of other stories that also contribute to its overall meaning. A *good* story does all these things *well*. The daughter's counterstory needs to be such a story, more dynamic than Gillett's tapestry but just as sweeping. And if it includes episodes of anger or betrayal, it had better also include the hand-drawn paper dolls the mother used to make for the daughter, the boxes of treats sent to her dorm room, the exquisite malapropisms the daughter finds so delightful. For the mother is surely all of that, and it's all of that to which the daughter must now respond. First, her hand needs a little medical attention. Then, her mother needs a little narrative attention. The relationship between mother and daughter has hit rock bottom, but with any luck, it will soon be on the mend.

NOTES

1. L. Wittgenstein, *Philosophical Investigations*, 3rd ed., trans. E. Anscombe (Oxford, U.K.: Blackwell, 2001), 152.
2. The author, writing as H.L. Nelson, *Identities Damaged, Narrative Repair* (Ithaca, N.Y.: Cornell University Press, 2001).
3. G. Chauncey, Jr., "From Sexual Inversion to Homosexuality: The Changing Medical Conceptualization of Female 'Deviance'," in *Passion and Power: Sexuality in History*, ed. K. Peiss and C. Simmons with R.A. Padgug (Philadelphia: Temple University Press, 1989).
4. G. Gillett, "You Always Were a Bastard," *Hastings Center Report* 32, no. 6 (2002): 23-8.
5. *Ibid.*, 25.
6. *Ibid.*, 27.