

## HOLDING ONE ANOTHER (WELL, WRONGLY, CLUMSILY) IN A TIME OF DEMENTIA

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**Abstract:** This essay takes a close look at a species of care that is particularly needed by people with progressive dementias but that has not been much discussed in the bioethics literature: the activity of holding the person in her or his identity. It presses the claim that close family members have a special responsibility to hold on to the demented person's identity for her or him, and offers some criteria for doing this morally well or badly. Finally, it considers how even those with dementia can hold others in their identities, and suggests that this kind of holding too can have great moral worth.

Keywords: dementia, identity, recognition, family, home.

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When I was very little, my Granny, who has lived in the Deep South all her life, used to sing me the Dixie version of "Froggie Went A-Courtin." When she got to the refrain, her glittery-ringed hands with their fascinating long red fingernails would beat out "Straddle-laddle laddle laddle, Laddle bobaringtum, Ringtum bottom getchee cumbo!" and we would both dissolve in a puddle of giggles. Granny was too bossy to let anybody into her kitchen, but she would allow me to sit at the counter and watch her cook, and pass me a bite when she thought my mom wasn't looking.

Like many other women of her time and place, Granny was a law not only unto herself but unto the rest of us too. She'd light into Gramps for tracking dirt on the carpet or threaten to go after the next youngun who left the front door open, and my daddy regularly got the Come to Jesus lecture about his not bringing us all to see her more often. When she wasn't laying down the law, though, she was a great one for laughing. Best of all was when she would try to tell a story against herself, because she would invariably crack herself up so badly as she went along that she couldn't finish.

Granny loved Gramps, of course, and my Aunt Biz and my mom and all the grandchildren, but my daddy was the apple of her eye. "Are they being good to you up there in that office," she'd ask, "and not working you too hard? You look kind of peaky to me." Dad would assure her he was fine, but she'd shake her head and say, "Well, that's all right but you can't get good boiled peanuts up there like you can here. I fixed you some for after supper." And sure enough, after the dishes were done and the stories were over and Mom told us it was time for bed, Granny would get out the bowl of cold boiled peanuts and

plenty of newspapers for the shells, and Dad would sit cross-legged on the floor by Granny's chair, shelling and eating them while she scratched his head as if he were a cat. We could almost see him purr.

Flash forward many years to when the personality of the woman I am calling Granny suddenly begins to unravel as the result of what is probably a multi-infarct dementia. Then the narrator of my story, her father and mother, and the other members of Granny's family become responsible for her care. In this essay I take a close look at a particular kind of care that is best provided by family members rather than professional caregivers: I call it holding the person in her identity. Because strangers cannot well provide this kind of care, I argue that family members have a special responsibility to hold on to the person's identity for her, and I offer some criteria for doing this morally well or badly. But then I consider how even those who most need to be held can hold others in their identities, albeit clumsily, and I suggest that this kind of holding too can have great moral worth.

### **Familial Responsibility to Hold**

In the sense in which I am using the term, an identity is a representation of a self. It consists of a tissue of stories, constructed from not only first-person but also many third-person perspectives, depicting the more important acts, experiences, relationships, and commitments that characterize a person and so allows that person and those around him to make sense of who he is. Because we change over time, some stories in the narrative tissue cease to depict us faithfully and—ideally—recede into the background, to be replaced with newer narratives that—again ideally—represent us more accurately (Nelson 2001).

Families are the primary sites for identity formation, which often begins even before birth, as the pregnant woman and other family members call the baby-to-be into personhood (Lindemann 2009). They do this through material practices (such as borrowing a crib or knitting tiny garments) that welcome the child into the family, but they also do it by weaving around the expected infant the stories that form its proto-identity. Mostly, these will be stories of relationship—narratives that identify the child to come as a member of *this* family, the son or daughter of *these* people. But the tissue of stories will also contain master narratives—the familiar stories permeating our culture that serve as summaries of socially shared understandings. These are the stories the family will likely draw on to make sense of the fact that the child will be a girl, or Irish American, or deaf, and so on.

As the child grows out of infancy she *becomes* who she is through the mutual process of accommodating herself to her family and being accommodated by it (Minuchin 1974, 47–48), but she *understands* who she is—acquires the self-conception out of which she acts—by means of

the stories which her parents and other family members use to constitute her identity, and which they tacitly or explicitly teach her to apply to herself. **Two kinds of stories are required to represent selves that are continually growing and changing even as in some respects they remain the same.** The first kind is **backward-looking**; these stories depict who someone is by offering a causal explanation (“She’s feisty, all right. Even in the womb she kicked like she meant it”). The second is **forward-looking**; these set the person’s future field of action (“When you’re older you’ll be a good speller just like Charlotte, only without the web”). While later the child will almost certainly challenge some of these third-person stories, as a young child she does not yet possess the critical skills necessary for challenges of that sort. It is third-person contributions, then, that first form a person’s identity.

All this is to say that families do the work of constructing their children’s identities, but not yet to explain why this is morally important work, and why families bear a special responsibility for doing it well. **Our identities matter morally because they function as counters in our social transactions, in that they convey understandings of both what we are expected to do and how others may or must treat us.** Because I am your mechanic, I am expected to know why your car is making that funny sound; because you are the mayor, you get to say how the city is run. **However, if families impose identities on their children that stunt their emotional, intellectual, or physical growth** (“You’ll never amount to anything”; “You’re too clumsy to try out for Little League”), they unfairly constrict their children’s agency and diminish their self-respect, and unless the children later manage to contest and repair these damaged identities, their lives will go badly for them. Because they are so well positioned to shape their children’s self-concepts and so much rides on the outcome, it is morally incumbent on family members to get the process of identity formation off to a good-enough start.

Just as families are primarily responsible for initially constructing the child’s identity, so too are they primarily responsible for holding the child in it. They do this by treating him in accordance with their narrative sense of him, and in so doing they reinforce those stories. **But identity maintenance also involves weeding out the stories that no longer fit and constructing new ones that do.** It’s in endorsing, testing, refining, discarding, and adding stories, and then acting on the basis of that ongoing narrative work, that families do their part to keep the child’s identity going.

**As she grows, of course, the child contributes more and more to this process herself, as do her playmates, teachers, neighbors, and the others she encounters in her life.** And just as important, these others challenge her, interrupt certain patterns of behavior, encourage self-transformations of various kinds, help or force her to grow in particular directions (Kukla 2007, 399). But when the kids at school call her names, when

her older brother tells her she's adopted, when she doesn't pass the exam—when, in short, her grip on herself is temporarily shaky, what she needs most is to be *held* in her identity. It is then that the adults in her immediate family have the special job of reminding her, by how they interact with her, of who she really is.

It's not only other people who hold us in our identities. Familiar places and things, beloved objects, pets, cherished rituals, one's own bed or favorite shirt, can and do help us to maintain our sense of self. And it is no accident that much of this kind of holding goes on in the place where our families are: at home. "The home," observes Iris Marion Young, "is an extension of and mirror for the living body in its everyday activity," and thus is "the materialization of identity" (Young 1997, 150). Our homes *manifest* who we are at the same time as they provide the physical scaffolding that *supports* who we are. They are the solidly familiar axes around which our changing world revolves. I won't develop this notion any further here, as the primary focus of my essay is on the narrative activity at the heart of person-to-person holding. Nevertheless, home-to-person holding can be enormously important, as we shall see later.

### Good and Bad Holding

There are times when all of us need to be held in our identities, even after we are old enough to do much of this work for ourselves. Indeed, some identities require others to hold us in them continually: I can't be your wife if you stop being my husband, for example. However, just as there are morally admirable as well as morally culpable ways of being a husband or wife, so too are there both admirable and culpable ways of holding each other in these—and all other—identities.

For an identity to be properly yours, the backward-looking stories that constitute it have to pick out something about you that is importantly *true* (Arras 1997, 81–82). If you never went to med school, aren't licensed to practice, and don't see patients, then you aren't a doctor, and neither I, nor your doting mother, nor God himself can hold you in that identity. This is not to say, of course, that one can never be held in an identity that is not properly one's own. Con artists and swindlers count on getting their victims to do just that, as might decent people in dire circumstances whose lives or safety depend on their ability to deceive their enemies. In these cases (by contrast to the case of the would-be doctor who never sees patients), deceivers *act* the part, and this makes it possible for others' identifying stories to represent something that resembles the person the imposter claims to be. The point I want to press, though, is that occasions on which it is morally good to hold people in identities that are not their own are very rare. Good holding almost always requires stories that depict something actual about the person, so if your stories portray him

as you wish to see him rather than as he actually is, you are very likely holding him wrong.

Truth is generally necessary but not sufficient for good holding. **The stories one uses to constitute the other's identity must also get the proportions right.** It may be perfectly true, for example, that your co-worker told a lie, but that by itself does not license your seeing her as a liar. For her to be fairly held in the "liar" identity, the lies must be habitual and serious enough to count as something other than polite euphemisms. Getting the proportions right might also mean taking into account who the person has been, and constructing a credible story of why a particular characteristic that formerly contributed relatively little to the overall shape of the identity is now so prominent a part of who she is. Or it might require discarding a story as too heavily focused on a characteristic that used to be important but no longer matters very much.

In addition to truth and proportionality, **good holding also usually requires that the stories constituting the identity keep open the person's field of action,** for this is how the narrative tissue captures the way in which selves are continually moving targets. One set of stories that closes down that field are the hateful or dismissive master narratives used by the members of a dominant social group to justify their oppression of another, less powerful group. These identities—black men as violent drug dealers, gay men as pedophiles, women as lovable nitwits, and so on—**unjustly constrict the agency of those who bear them, keeping them from pursuing desirable opportunities and from enjoying their fair share of the goods that society has to offer.** Good holding requires us to weed out these oppressive narratives from the stories we use to identify anyone.

There is another set of stories that constrict people's agency. By contrast to morally degrading master narratives that misrepresent entire *classes* of people, *individually* constricting stories might be both true and correctly proportionate but fail to hold well because they look only backward and never ahead. When we interact with someone solely on the basis of these stories, we impede the person's ability to change. As Rebecca Kukla puts it, "In order to let a loved one show herself as herself, we often need to do more than perceive her as she really, already is; we need to offer material assistance and uptake that enable her to *become* . . . who she is" (Kukla 2007, 398; my emphasis.). Often, this becoming involves some kind of growth: the stories in the narrative tissue must acknowledge that your teenager really is a slob but leave room for him to reform. At other times, though, the change is in the other direction: the stories that constitute your sister as invariably well dressed still capture something important about her, but now that she is in the grip of Alzheimer's disease, you may have to help her adjust—and adjust yourself—to a more relaxed standard. **The only instance that comes to mind where an identity properly consists solely of backward-looking stories is when the person becomes permanently incapable of interacting**

in any way with those around her. People in the persistent vegetative state or in the end stages of dying are held badly when their loved ones draw on master narratives of miracle cures or mysterious awakenings that project the person into a future she cannot possibly inhabit.

### Clumsy Holding

A distinction can be made between wrongful holding and clumsy holding. To make it, I continue the story with which I began.

When Dad called to tell me that Aunt Biz couldn't take care of Granny by herself anymore and there was no money for a home health aide, he sounded upset. "Biz is frazzled and at the end of her rope. She found a nice nursing home," he told me, "but she wants me to come down there to help her convince Mama she's got to go to it. And considering that Mama isn't thinking straight these days and always was pig-headed, there's going to be no reasoning with her."

I knew my duty as a daughter, and I did it. "I'll meet you down there," I said.

As it happened, Granny grew so frail in the three days before I arrived that she put up no resistance to being moved. She couldn't make sense of where she was, and kept referring to the nursing home as "that woman's house," as if she were a guest and trying to be polite about it but was clearly ready for the visit to end. Worse were the paranoid delusions, which mostly concerned enemies out to get, not her, but Dad or sometimes Gramps, now dead for many years. Sometimes she would recognize Aunt Biz and Dad and me, though often she would call me by her sister's name or think Dad was her husband. And sometimes she would just cry quietly and wonder what she had done to make everybody so mad that they wouldn't come see her anymore.

One day I gave her a manicure and pedicure, and I think we both felt better when her fingernails were shiny red again. Dad played his guitar for her, and that helped to steady her a little too. Mostly, though, we just sat with her, listening to her disjointed stream-of-consciousness observations, coaxing her to eat a few bites, and watching over her as she slept. On the final day of our stay, she wasn't quite sure who we were except that we were family, but she grasped that we were saying goodbye.

"Now, I'm going to be brave and not cry until after y'all leave me," she told us. "Come here, Buddy—Earl—Jasper, and let me scritch you before you go."

So Dad sat down again in the chair by her bed and Granny scritch his head for a while. When she finished, his hair was standing on end so she asked me for a comb and began to smooth it down. After she'd fixed it to her satisfaction we kissed her goodbye, and drove to the airport without talking very much and flew home.

There are many kinds of holding going on here, beginning with the narrator's decision to join her father, by which she holds him and her grandmother as well. By coming when he is needed, the father holds his mother and Biz. The manicure is an act of holding; the guitar playing

could be another. By the criteria I've just offered, both father and daughter hold well, acting on the basis of backward-looking stories that are still relevant and accurately supplying forward-looking stories that make room for the grandmother's current fear, progressive disorientation, and increasing helplessness.

The most striking form of holding, of course, is the grandmother's of the father. In this Southern-style *pietà*, Granny holds Dad not well but clumsily, out of a fragmented and chaotic self-concept and an equally chaotic narrative understanding of who this man is. Her grip—on her son, on herself, on reality—is wobbly and unsure, yet for all its clumsiness, I submit, her holding is nevertheless a genuine exercise of her moral agency. It doesn't matter that she is no longer capable of rational reflection or of understanding her own situation. It doesn't even matter that she is no longer clear about whose identity, exactly, she is maintaining. Those considerations keep her from being able to hold well, but they don't stop her from holding clumsily. It is enough that she places this Buddy—Earl—Jasper fellow somewhere in the vicinity of her son, so that although her stories have disintegrated and her words have failed her, the holding still goes more or less where she intends.

I earlier referred to holding as a particular kind of care, and so it is: it is a part of the work of preserving, maintaining, and nurturing people. Joan Tronto has argued that morally good caring requires: (1) attentiveness to the needs of the (potential) recipient of care; (2) taking or accepting responsibility for meeting those needs; (3) competence in performing the tasks of care; and (4) responsiveness of the recipient to the care (Tronto 1993, 127–37). If these are the right characteristics, then presumably bad caring is inattentive, irresponsible, incompetent, and not attuned to the recipient's response.

Notice, though, that clumsy holding can be characterized in these ways as well. Although the grandmother in my story is attentive, she doesn't exactly know whom she is attending. She can scarcely be held responsible for anything she does these days, and she certainly is not competent in any legal or moral sense of the term. Furthermore, something has gone seriously wrong with how responsiveness is supposed to work here. Tronto writes, "Responsiveness suggests . . . that we consider the other's position as that other expresses it. Thus, one is engaged from the standpoint of the other, but not simply by presuming that the other is exactly like the self" (1993, 136). If engagement from the standpoint of the other is the mark of responsiveness, the grandmother doesn't even begin to qualify.

Nevertheless, although she meets none of the criteria for ethical caring, the grandmother's way of holding her son in his identity has tremendous moral worth. The elements Tronto has identified do indeed mark the difference between caring badly and caring well in many ordinary interactions, as between health professionals and patients, for instance, or teachers and students, or parents and young children. But the

devastating beauty of the grandmother's action suggests that there are other sources of goodness that can make caring morally valuable—sources that do not require the levels of cognition presupposed by Tronto's list. In holding her son as she does, I believe, **the grandmother draws on the long history of her relationship with him from infancy to adulthood, through tantrums and tenderness, fear and fair weather, sorrow, pride, and all the rest. Their entwined lives have held enough goodness so that now, when cognition is largely gone and little but habits of feeling remain, she still has a way to express how much she values her son.**

A final thought: societies too have a role to play in helping us hold on to one another. **If the familiar places and objects of home importantly hold us, it is better for us, all things being equal, to stay in our homes as long as we possibly can.** However, when home care for people with progressive dementia is left almost entirely to family members, the familial capacity for care may be exhausted well before the benefits to the demented person of living at home have come to an end. In the United States, a nursing home then becomes the only option for many people, as Medicare covers home health care only on a part-time or intermittent basis (Medicare 2007, 3) and most private health insurers offer only very limited coverage as well. This state of affairs is not inevitable. **Had the grandmother in my story been able to remain in her home, with adequate professional help and a carefully structured daily routine, she might not have gone downhill so rapidly.** Social institutions and practices could be arranged so that the goods of home were integrated into the other forms of care. **Eventually, nothing will keep the selves of progressively demented people from coming completely undone, but until then, they and their caregivers need the rest of us to hold them—if not as well as we can, then at least better than we do.**

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