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Moral Self-Orientation in Alzheimer's Dementia

ABSTRACT. People with Alzheimer's dementia experience significant neuropsychological decline, and this seems to threaten their sense of self. Yet they continue to have regard for their moral standing, especially from the feedback they receive from others in relation to such things as pride in their work, retaining a valued role, or acting out of a sense of purpose. This continuing self-regard is based on a self-image which often persists through memory loss. I will argue that in care settings the self-image ought to be assumed to remain intact. Treating a person with Alzheimer's dementia supportively and respectfully as the person with a certain role or identity—say as scientist, musician, janitor, parent, or friend—fosters an environment in which they are best able to retain what I call moral self-orientation. The latter notion is central to the well-being of social persons, and so it takes on special significance for people with dementia because, although their remembering selves are fragmenting, their self-image persists. Normative aspects of the self-image, I argue, require a social framework of support to sustain the self-image.

INTRODUCTION

It is ordinarily thought that in Alzheimer's dementia (AD), memory loss leads to a loss of the self. There is a familiar sense in which this is true given that there is, evidently, a close connection between episodic memory and personal identity. This view goes back to John Locke who argued that remembering our own experiences enabled the continuity of consciousness he thought constitutive of personal identity. Locke was also motivated by the idea—to be applied in “forensic” contexts—that continuity of consciousness was necessary in the appropriation of past actions as one's own (1694). As we will see there is another type of connection between a person's psychology and morality—not involving questions of accountability—that may hold even when episodic remembering capacities have been lost. This is because there are persons whose AD brings with it quite profound breakdowns in episodic remembering—and so gaps in the

ability to track continuity of consciousness—and despite these gaps such persons retain an understanding of who they are.¹ This understanding is constituted by what psychologists refer to as their trait self-knowledge, self-concept, or self-image (my preferred term for this context). The self-image contains evaluations of self, including of special interest here, moral evaluations. These evaluations are modulated by interpersonal exchanges, and so this persisting self-image continues to be, in social settings, sensitive to reward and to injury. For example, those with profound episodic memory loss often do not lose their selves understood as the objects of pride and purpose and as a source of meaningfulness. Their ongoing responsiveness to others' treatment of them frames their sense morally of who they are. A lack of respect or recognition is hurtful and isolating; acknowledgment of a valued role or appreciation of a good deed done is a source of happiness and meaningfulness. This ongoing responsiveness is supported by those retained cognitive-affective capacities that situate the moral self in social or dialogical space. I will call these retained capacities the *moral self-orienting emotions and attitudes*, and I will call the process in which they operate *moral self-orientation*. When the machinery of moral self-orientation functions well, a person's self-image is rendered stable, coherent, and valued. When it does not, alienation, stigma, rejection, or worse still, an identity crisis threatens. In fact, these threats potentially afflict us all, but when they afflict a vulnerable person with AD, who is already facing struggles brought on from cognitive decline, the endangerment to their self-image is greatly magnified.

DR. B

Georgetown University neuropsychologist Steven Sabat describes the case of Dr. B, a retired professor with “moderate to severe” AD (2018, 57).² Sabat was conducting a study into the subjective experience of AD at the day center where Dr. B resided. For nine months they met for two hours each week to work on this project. Dr. B had deficits in episodic memory, difficulties in reading and speaking, could not dress himself, and frequently lost track of his thoughts. Nevertheless, he retained a keen insight into his condition, and could reflect accurately on his experience despite the fact that, as he put it, “things get jumbled, and Alzheimer's gives me fragments” (2018, 63). Although he lacked the capacity to unify his experiences across time, he nevertheless had an ongoing sense of this disunification; he grasped what it was like; he retained insight into the fact that his Alzheimer's was causing him losses in his ability to stitch

together his day-to-day experiences into some kind of coherent narrative form. It was the retention of this insight that was the source of his general unhappiness. He had become frustrated by his disease, something he said that was “constantly on my mind” (2018, 58).

Dr. B might not remember what he did an hour ago, yesterday, or last month, so information normally extractable from such mental time travel was unavailable to him in the formation of his understanding of who he was. But this understanding, particularly around his status and role as a scientist, remained intact and importantly continued to govern his interactions with those at the day center. It was important to Dr. B that others perceive him under the evaluatively toned description he assigned to himself. But Dr. B's aphasia made it hard for him to tell others at the day center about the valuable things he was doing. To address this Sabat mentions that he arranged for a letter from his Dean to be sent to Dr. B in recognition of his positive contribution to the project. Dr. B then carried with him a photocopy of the Dean's letter, which could be produced and used to speak on his behalf. It was, said Sabat “tremendously important to him that he not be defined by AD and the dysfunctions it causes” (2018, 72). Dr. B retained relatively accurate knowledge of himself that mattered to him and that he wanted others to know about and respect. It was important to Dr. B that he continue to be recognized by those around him in the day center as someone of moral standing. This is because his standing as a scientist constituted the main measure of this self-esteem.

In the present context I focus on the importance we place upon moral standing and the ways in which the emotions and attitudes of social agents frame our sense of this standing, that is, our *moral* self-orientation.³ Dr. B's disposition to be valued in this way is not, according to Sabat, picked up by the standard neuropsychological tests, tests that typically measure cognitive competencies of various sorts. This is problematic, especially if caregivers rely on them in order to get an accurate picture of those in care so that *they* are properly oriented towards them. Discharging their role properly and sensitively depends on accurate understandings of those in care, partly to avoid misapprehensions or even stigmas arising from a lack of information. Those false beliefs can exacerbate the problems in the care relationship when, for example, they feed back into the everyday dialogical exchanges between carer and resident. For example, (public) stigma is well known to feed the process of self-stigmatization, a process in which the shamed persons mark themselves out to themselves as spoiled, compromised, different, or less than human in some respect; that is extraordinarily damaging to moral self-orientation.

Sabat asks “Do people...with dementia need and want purpose in life? Do they have a sense of proper pride and self-respect?” (2018, 69). He answers, emphatically, “yes, they definitely do.” He points out that the research he was doing with Dr. B was tremendously important to him. It was, as Dr. B described it, “a scientific sort of thing...[and] we can get glory [from it]” (2018, 69). Sabat mentions that Dr. B asked the director of the facility to post a sign on the bulletin board with the times he would meet the professor to work on the project; he felt this would differentiate him from the others. He also made himself available to Sabat’s students and continued to refer to himself as a scientist. “In terms of his disposition, habits of mind, and his sense of who he was, he was very much a scientist” (2018, 70). Sabat continues,

His proclivities were clear in the way he comported himself at the day center, so it would be utterly wrong to say about him “He used to be a scientist.” Indeed, Dr. B, in talking about himself and his wife of many decades, said, “Well, my wife and I are very strong academic people and, uh, so we start talking to each other, we talk to each other at a very high level right away.” This plainly indicates an aspect of his disposition that he valued greatly and needed to be recognized and respected by others and now, especially, nurtured. (2018, 70)

THE FEATURES OF MORAL SELF-ORIENTATION

It is clear that Dr. B possesses a range of emotions and attitudes that enable him to engage in the process of moral self-orientation. We can identify several key features of these emotions and attitudes. First, they involve a reflexive attitude, one that takes as their object a self—Dr. B feels pride in *himself*. Second, their occurrence is phenomenologically rich, especially insofar as they provide meaning and significance for those who experience them—for Dr. B it was pride in his role as an academic person which continued to motivate him and make his life meaningful in spite of his disabling cognitive decline. Third, to enact such emotions and attitudes is to exhibit moral insight—Dr. B’s activities with Sabat were partly generated by the thought that he not only could help, but he *ought* to help those at the day center; and others *ought* to offer recognition for who *he* was, a person whose role was morally important. And fourth, the moral self-orienting emotions and attitudes are epistemically grounded in social relationships—for Dr. B’s pride and self-affirmation to be properly constituted required a social framework in which close others regularly provided validation. Let me now consider each of the features in more detail.

Dr. B's pride provides a clear illustration of the reflexive dimension of the moral self-orienting emotions and attitudes. By 'pride,' I do not mean, of course, a vain disposition, but rather pride taken as synonymous with that self-respect accompanying an achievement or role, which gives rise to the justified expectation of equal treatment and recognition of status. In this sense, Dr. B takes pride in himself especially insofar as he identifies with his role as a scientist, and his work within the day center with Steven Sabat. Such identification requires that he disclose himself to himself, considered as a creditworthy person, so it requires some understanding both of his own traits, together with their evaluation.⁴ It is noteworthy that psychologists include evaluative content as part of trait self-knowledge. For example, Shaun Nichols (2012) quotes the social psychologist Jason Mitchell (2009, 247) who writes the following:

The self-concept [or self-image] refers to a person's understanding of what she "is like" as a person, that is, what personality characteristics she manifests, what idiosyncratic abilities and proclivities define her as an individual, and *to what extent she regards herself positively (i.e. has high or low self-esteem)*. [my emphasis]

Trait self-knowledge can be directly evaluative in this way or implicitly so, given the moral meaning and significance attaching to roles and traits we think of ourselves as having. Either way, having a conception of yourself with evaluative content turns out to be important in terms of what one cares about, what one finds meaningful and significant, and what one is thereby motivated to do. As we will see, these considerations are important to the way a supported self-image articulates with effective agency, insofar as one can act in line with a valued role.

On the second feature of moral self-orientation, the emotions and attitudes associated with it provide a rich sense of what is meaningful and significant to a person by virtue of the self-image they support. The first symptoms of AD include short term memory loss leading to fragmentation of narrative continuity in one's sense of (especially) the recent past. The experience of this loss in the unity of one's story varies between individuals, as does the emotional response. Some people become depressed; others are more sanguine. As I will argue, however, it is one thing to lose your story in the sense of having gaps in autobiographical knowledge, another to experience changes to your self-image. The self-image is phenomenologically rich; it includes your sense of how you see yourself as faring relative to others, your status, and your self-acceptance as a certain kind of person, a person with an esteemed or useful role, for

example. Sabat describes the case of Mr. K and his wife who was at the day center along with Dr. B. Mr. K had previously done everything for his wife while at home, but this meant she had virtually nothing to do, and this was at odds with her previous roles in the service industry. At the day center she had been given a range of tasks, such as setting tables, helping people in wheelchairs, and so on. Sabat says,

although he was filled with good intentions, [Mr. K] unwittingly prevented her [while at home] from experiencing the kind of meaning and purpose she revelled in, for she had always been a service-oriented person. (2018, 74)

The third feature involving the moral self-orienting emotions and attitudes is moral insight. The thought here, more precisely, is that the engagement of these emotions and attitudes presupposes an understanding of the moral concepts governing interpersonal exchanges and relationships, including especially continuing to take on the responsibilities of one's position, or of the recognition and respect that is due in virtue of them. Sabat describes the case of Mrs. F, who tried

to continue to be a worthy, helpful partner....She went around the house, seemingly in the act of tidying up, but put objects in places where they should not be put normally....She was clearly aware that she was not being the wonderfully accomplished and helpful partner [she had been]....She said to her husband very poignantly, "I'm no good for you," thereby reflecting a very well-developed ability to evaluate her actions past and present as well as a sense of the deep anguish she was experiencing at present. (2018, 77).

Sabat further elaborates the theme of retaining a sense of self in relation to how it affects moral status and role. In this connection the self-orienting emotions and attitudes play a protective role in maintaining the moral self; they form a buffer against threats to it that arise out of failures of recognition. In the case of Dr. B, being part of Sabat's research project served a dual purpose insofar as it was an activity enabling him to prolong his sense of what his true role was and at the same time to provide him with the kind of standing he regarded as due to him. The disunification resulting from his anterograde amnesia self-evidently did not affect the possession of this moral self in as much as it was presented to others under the description of an esteemed role, namely the scientist that he was. He continued to value the idea that he be understood by others and treated well. Were he not to receive this recognition, or were others to downplay the significance of the role, there is reason to think this would lead to feelings of isolation, anxiety, perhaps even alienation. Dr. B's self-

confidence is precarious; he is racked by self-doubt. What holds this at bay is the knowledge that others—in particular Steven Sabat and the students he teaches—willingly attend to what he has to say. Sabat quotes one of the students, Heather Markey, who said “[Dr. B] was a wonderful man who taught us all so much....No other person and no book could have taught me as much as Dr. B did” (2018, 70).

The fourth feature of the moral self-orienting emotions and attitudes is that they are grounded in a social framework. The source of Dr. B's pride in his role derived from the social environment wherein he was enabled to continue his scientific work. Mrs. K's being allowed to continue in her service role at the day center also meant that she could engage with others in the center on that basis, as having that role. Since she could be treated as the kind of person whose agency was structured by that role, conversations around her activity might feed back into her sense of what she was doing, thereby reinforcing the very activity she was engaged in. Her self-image was thus reinforced in this relational way. This fourth feature, I will later emphasize, is central to the main case for what is important about the process of moral self-orientation. One's self-image depends in important ways on feedback from others, or in other words, one's self-image is partly a *relational self*. The relational self should matter a lot in cases of AD, where another source of autobiographical knowledge has gone missing.

THE UPDATABLE SELF-IMAGE, THE PETRIFIED SELF-IMAGE, AND THE LIMIT CASES

That the moral self-orienting emotions and attitudes remain in place for those with AD implies that there is a self that also remains. To feel pride or shame requires the invocation of a self to be presented inwardly as the object of those very emotions. To feel pride is to be proud of oneself; to feel shame is to be ashamed of oneself. Some other examples include self-respect or trustworthiness, and negatively, self-hatred, humiliation, or disgrace. In each case the attitude goes beyond some specific happening or action; its object is a conception of who they are. Yet for those with AD who have memory loss, this is not the self that is delivered via a state that reaches back in time to recent episodes. It is not an episodic self; it is the self that remains intact in spite of profound (episodic) memory loss; it is, as I am calling it, the self-image. The episodic self, in contrast, is aptly named: it does reach back to some specific happening or action in which it was involved.⁵

The conceptual separability of these selves is borne out by their being presented to the mind via distinct neuropsychological systems.⁶ It is worth

recounting some cases, and work done by neuropsychologists, to bring this into sharper focus.⁷ Klein, Cosmides, and Costabile (2003) report the case of K.R. who had AD:

Although K.R. has difficulty retrieving even mundane facts about the world, she has accurate knowledge of her own personality. But the self she knows is out-of-date. K.R.'s inability to update her trait self-knowledge stands in contrast to other neuropsychological cases in which individuals can acquire and update their fund of personality knowledge despite impairments to semantic and episodic memory....[Trait self-knowledge] is surprisingly resilient....It can be preserved without any retrievable episodic memory, as shown through [other] case studies of patients D.B.,...K.C., and R.J. Indeed, recent neuropsychological evidence demonstrates that individuals lacking access to episodic memory can, nevertheless, update their fund of [their own] personality knowledge. (157–8)

In these cases, brain damage knocks out a pre-existing memory system, without disturbing the trait self-knowledge which in turn supports the process of moral self-orientation. It is notable that Klein, Cosmides, and Costabile observe an important distinction between cases where the self-image can be updated and those where it remains stuck in the past, such as for K.R. It seems, by contrast, that Dr. B's trait self-knowledge was being refreshed daily; at the very least he did retain an insight into where he was and that his role as an academic person was being brought to bear in that context.⁸ There are other cases of people who enact a role they occupied decades ago and mistakenly treat their dementia facility as a place where that role continues to apply. Sacks (2019) discusses the case of Mr. Q, a former janitor who continued to enact this role in his nursing home run by the Little Sisters of the Poor, checking windows and doors so that they were locked, inspecting laundry and boiler rooms to see that all was functioning well, and so on.

It might be thought that in cases in which the self-image is out of date, the process of moral self-orientation is rendered morally problematic since it requires systematic deception by caregivers. Does truthfulness matter here? In cases like that of Mr. Q, the answer is surely that it does not. Were the Sisters to insist on the truth—"You are no longer a janitor, you ceased that role a decade ago, and you have Alzheimer's disease; this is an aged care facility"—this would potentially cause confusion, agitation, even grief. Sacks puts the point this way:

The sisters...though perceiving his confusion and delusion, respected and even reinforced [his] identity...they assisted him in his janitorial role, giving

him keys to certain closets and encouraging him to lock up at night before he retired....And, though he slowly became more and more demented over the years, he seemed to be organized and held together in a remarkable way by his role....Should we have told Mr. Q. that he was no longer a janitor but a declining and demented patient in a nursing home? Should we have taken away his accustomed and well-rehearsed identity and replaced it with a "reality" that, though real to us, would have been meaningless to him? It seemed not only pointless but cruel to do so—and might well have hastened his decline.

Another way of seeing the point is to view the Sisters' response to Mr. Q as one in which they preserved his self-image by maintaining the stance of moral self-orientation. That the self-image is "petrified" seems beside the point.⁹ There is also a question concerning whether Mr. Q in fact retains the ability to be lied to. Schermer (2007) has argued convincingly that, in many cases of advanced Alzheimer's disease, the cognitive capacities needed to entertain concepts and to form stable beliefs have deteriorated too far. If this is correct, the moral question concerning whether it is right to go along with a (strictly) false identity is rendered moot; since there is no painful alternative, Sacks's conclusion surely goes through.

Yet it would be hasty and unwise to generalize from the rather neat case of Mr. Q. There are cases in the moderate range of AD where insight may be flickering, where the person has moments of clarity, lucidity, and understanding of their condition and the effects on those in the situation, and then shortly after, periods where this is gone, and confusion or a strange identity enters the fray. In one sense these are the hardest times for carers because when the identity of the person they love or care for is not stable, knowing how to respond becomes an hour-by-hour guessing game. Consider this excerpt from a recent interview with Irene Jacobs whose husband David developed Alzheimer's.

It's this sort of strange loss of control. It's a mental loss of control because he has insight and he will come to me as a very caring loving person and be so sorry for what's happening. Now that's an awful insight for him and sad, sad for him and he is sorry for the weight that I carry. But then, because he has Alzheimer's, the next minute he can become a total, absolute awful, strange person, that's not that person. The person's gone – quickly, as if disappeared. It is bewildering beyond words.¹⁰

In this case the normal processes of interpretation that undergird close relationships cannot be applied—Irene's David is a person without a unified self-presentation, and so at this point there is simply no truthful,

stable, or useful interpretation she may conjure that can feed back into the relationship, to be taken up by David in any fruitful way. This case illustrates the limits of my thesis. David's self-image is not sufficiently unified and stable to allow the process of moral self-orientation to gain traction.¹¹

THE RESILIENT SELF-IMAGE AND THE VULNERABLE PERSON

In this section I make the case for the vulnerability of the person in dementia and why we need to take account of this in social settings where the self-image is exposed to what others do or say. There are two grounds for this case. First, in the later stages of AD the episodic self is missing, and autobiographical knowledge is fragmenting, leaving the person to overly depend on their self-image as the source of moral self-orientation. Second, for the self-image to endure in ways that support well-being and agency, it requires a healthy relational self, the self that is maintained in concert with others, and a key element of the fourth feature of moral self-orientation identified above. Putting these together, in short, the idea is that the individual with AD has impoverished psychological capacity relative to a time before to support personhood, and so they need to rely on others as external supports.

On the first point, we should take a step back to make some general remarks on the relation between selves and the individuals who have them. What are selves? Why are there so many of them? And is this a problem? To answer these questions let me first emphasize that I use 'self' here as a term of art, one that is designed to capture the idea of an individual who manifests under a certain kind of description.¹² Selves are the different faces individuals display inwardly to their mind's eye or outwardly to the world. For example, an episodic self is the self that manifests to the person in remembering past episodes. A self-image is the self that is manifest to the person in a conception of who they are and what they are like. In the normal case (and psychopathologies aside) phenomenologically it doesn't feel to the person who remembers, or who reflects on their character, that these selves dissociate, as though they might belong to different people. An episodic self is presented as a way of thinking about a person whose self is filled out by the content of their remembering. And a self-image is a way of thinking about a person whose self-regard is informed by a picture of what he or she is like.

That I am using 'self' in this way connects to the idea that positing selves is metaphysically harmless. I agree with Velleman, who says, "The word

'self' does not denote any one entity but rather expresses a reflexive guise under which parts or aspects of a person are presented to his own mind" (2006, 3). Such presentations are context- as well as function-dependent. Apart from the episodic self and the self-image already discussed above, there are the following selves: (1) the autonomous self that plans and acts; (2) the body-self that has a running conception of where the boundaries of the person begin and end; (3) the narrative self, that conceives its present position as a narrator within a larger story; and as mentioned (4) the relational self that is constructed out of its social relations.¹³ I don't say this list exhausts the field, but rather it is meant to capture something theoretically important and salient that persons do *as* selves. All that is required is that a person's mind present aspects of itself within a context, for a purpose, under a certain conception, or formed in a certain way.

That there are different selves presented to us in different contexts is not to say that we present only one self at a time. It may be difficult to pay attention to more than one self at a time, but there are many occasions in which our different selves must operate in parallel. Complex tasks such as managing a project, organizing a social occasion, or coaching on game day, require the operation of different selves that draw on episodic memory, autonomy, and narrative agency. Take the coaching example: memories of the way events during the game were handled, planning in the light of those events, and getting an overall sense of the story of the game must each present to the coach at a level apt for coordination at the executive level.

With this picture in place as requiring coordination of selves, we only need reflect on the difficulty of compensating for what happens when some of those selves are debilitated, even wholly subtracted, as happens in middle to late stage AD. Dr. B's episodic and narrative selves were severely under threat, partly due to his memory difficulties, but also partly due to his aphasic challenges, which meant (presumably) that his narrative stream of consciousness constantly faced hurdles to find the words to properly describe his inner reality. A narrator is lost without the words for the story, and this was Dr. B's problem, explaining why he carried with him the letter from Sabat's Dean. Dr. B's academic credentials must have made it doubly hard for him since an academic role requires facility in language. His self-image was already under siege then from the losses to selves that would normally support it. It would not take much for him to suffer further moral self-disorientation if others took up a stance towards him that did not recognize his remaining abilities and what he could contribute to the project.

In AD, psychologists report that the self-image is resilient, it persists while other selves—especially the episodic self—do not.¹⁴ That is partly why the self-image is the focus of moral self-orientation: it remains the pivotal center for this process when other selves are failing. It may, so to say, be the last self standing. And yet, as resilient as it is, in this condition the *person* is highly vulnerable when the self-image is questioned, threatened, belittled, resented, or in general treated badly. With little in cognitive reserve, a person's self-image needs extra protection.

We now turn to the second ground for acknowledging the vulnerability of the person in AD: the importance of the relational self. We can begin by recalling the fourth feature of moral self-orientation: that the emotions and attitudes grounding this process are ineliminably social. Our self-images are maintained through processes that are inherently relational. Given the extraordinary vulnerabilities arising through cognitive decline in severe AD, the relational dimension to the maintenance of the self-image assumes greater importance relative to the normal case. To establish this, I first explain what I mean by the relational self and what its connection is to the self-image. I then go on to discuss why the relational self is important in the formation of the self-image, especially given the cognitive stresses facing those in later stage AD.

Our relational selves are the selves we construct with others, particularly close others, such as family and friends. In their analysis of the concept of friendship, Cocking and Kennett (1998) argue that the relational self (and the value deriving from it) is generated through interactions which can lead to the co-authorship of selfhood. With close others often we respond positively to their invitations to engage in activities, and we participate in these on the basis that it is time spent *with them*; the activity itself is the vehicle for the friendship. Such events bring us together so that our agency together aims at a common end; I am motivated to pursue this end to be with my friend, and my friend is similarly disposed. This motivation is present even when I have little interest in the activity. Perhaps I am completely indifferent to bebop jazz, but nevertheless I find myself going along to a concert. I am directed to pursue it because my friend has made the suggestion that we go, and it is something she is interested in. Cocking and Kennett describe this element in friendship as *direction*.

The second element of close friendship is what they call *interpretation*. Friends disclose themselves to each other in how they present, in their behavior, in their conversations, mannerisms, and choices. In doing so friends interpret all of this content and (often enough) relay back to the

other an interpretation of the image that is so presented. In this way I come to see a version of myself through the eyes of my friend, and she sees a version of herself through my eyes. I notice my friend is nervous in certain social situations—her normally voluble self recedes, she uncharacteristically becomes tongue-tied, or she simply shies away—but she can't quite see all this the way I see it. My perspective on the situation can then figure in her understanding of what seems to have gone wrong. In a multiplicity of ways friends shine a light on each other's characters, leading to changes in the way they see themselves.

Direction and interpretation may be present to some extent in relationships that fall short of the friendship model, and really the interpenetration of self-narratives tends to occur almost any time we engage in social ways with another human being, even if only to a small extent. What we have, then, is a model readymade for understanding the ways in which especially close others co-create, and maintain, their self-images, including the values that attach to them. This can be because close others influence our behavior or because they provide a value-laden description of it, or of who we are, or because we internalize their evaluations of us. In this way we make ourselves vulnerable to them and to the ways they treat us; for example, with our closest friends we relinquish personal privacy often to a quite significant extent. We regularly need the cooperation of others, and other people contribute very significantly to how we see ourselves; our characters are thus shaped by these interactions.

The self-image cannot be understood fully without an understanding of how the relational self informs it. This is because the self-image, as I define it here, is normative, and the sources of this normativity do not spring from the lonely agent; they are ineliminably inter-subjective. Moreover, those identity-orienting emotions and attitudes like shame or pride depend on standards we filter through our understanding of what others think of us and of how they react to us. Dr. B was evidently aware of these standards and reacted accordingly. He retained a proud sense of his role as scientist and the scientific work he was taking part in at the day center. Dr. B's episodic self—his picture of himself based on his capacity to track past experiences—could no longer provide him with information about who he was. Yet Dr. B's self-image remained relatively intact, as well as his sensitivity to those around him who were able to sustain it, (perhaps) to do it damage, or to neglect it. Dr. B relied on his interactions with others in order to make up for the remembered self that no longer presented to his mind. His relational self remained in place.

The moral self-orienting emotions and attitudes target our self-image. They are, conceptually, such as to be triggered by others' responses to us, and in the light of interpretations we place upon those responses, shaped by our receptivity to them. The sense of pride at stake in Dr. B's case structured a relational identity he was able to maintain and even develop; it ordered his thoughts about himself and others, and it oriented him with respect to the relationships he could sustain. By structuring his relational identity, I mean that the science project he was engaged in could be *interpreted* by him and those close to him as an achievement and so (at least from his point of view) as a basis for harmonious relationships within the home. Others, seeing that Dr. B occupied a valued role in an experiment to study dementia, then had a basis upon which to understand him in that way and to value what he was doing.

MORAL SELF-ORIENTATION, PURPOSE, ROLES, STATUS, AND AGENCY

Thus far I have emphasized how important the relational self is to the self-image, as well as the mechanism for translating that relation: paying close attention to those retained emotions and attitudes that provide moral orientation for a person with AD. This contributes to their well-being, but more needs to be said about the way moral self-orientation feeds into agency, something that is typically under serious threat in AD. In this section I explain how the maintenance of a healthy self-image supports such agency. At a fundamental level the idea is that without an understanding of who you are (including your role or purpose) and without an appreciation that this is an important thing (as supported by those around you), you will lack what is required to understand what you are supposed to do and to be motivated as such.

J. David Velleman claims that agency tends to require a consistent self-attribution of motives and traits, coupled with the cognitive motive to see ourselves as intelligible and predictable (2006, 243). For those with AD whose longitudinal narrative selves are fragmenting due to memory loss, a persisting self-image becomes critical to maintaining agency. It thus matters that the relational self of those with AD is supported to ensure ongoing intelligibility of role. The external environment, including its caregivers, becomes an essential framing factor to this ongoing intelligibility. To see how this works, consider that many of those with AD retain the capacity for purpose in their daily lives, and this is borne out particularly in cases where the purpose is exhibited in helping behaviour. Dr. B contributed to the project; Mrs. K provided her services around the care facility;

Mr. Q made sure doors and closets were locked; and Mrs. F continued (at least to aspire) to be a helping partner around the house. Evidently these activities, at least for a brief period, gave their lives structure and meaning and a greater sense of well-being. Sabat mentions that Dr. B made himself available to his students in clinical neuropsychology, the purpose being to help them understand what it was like to have AD.

Sabat describes a conversation he had with Dr. B in respect to the status attaching to his role and help in the project, something of importance to moral self-orientation. Dr. B asks him, "What keeps you going about me?" (2018, 100). Sabat tells him there are things he can still do and that he has a lot to teach about Alzheimer's, especially insofar as the person with the disease is not well understood. Sabat then explains that "It's a matter of human dignity," to which Dr. B responds: "Well, I got a lot of dignity" (2018, 101). Sabat's comments on this conversation are insightful and capture an important point about the importance of role-based agency to dignity and well-being.

For a person to ask such a question [What keeps you going about me?] reveals the need for reassurance that there is something about the person worthy of interest...and of the work we did together. For Dr. B to have asked that question also reveals his own feeling of being safe—safe enough to ask and to hear the answer. His feeling of vulnerability [was quite clear from the conversation]. (2018, 100)

Dr. B, then, feels safe, accepted, and morally oriented because of who he is, a scientist. Although memory loss gives him "fragments" in negotiating day-to-day life, Dr. B's retained self-image, as with Mr. Q, had the effect of holding him together, and 'organizing' him, especially when the exigencies of the role demanded certain tasks be completed in line with it. Let me now develop this point with some general remarks about how self-image (and the values it inscribes) articulates with action.

There is evidently a wide-ranging connection between valuing or caring and agency, and that is the way an esteemed role provides a way of translating the thing valued into deeds done for the sake of the value. In this connection Dr. B's pride in his work and role can be fruitfully compared to what Frankfurt (1982) was talking about when he drew attention to the importance of what we care about. He wrote the following:

Caring, insofar as it consists in guiding oneself along a distinctive course or in a particular manner, presupposes both agency and self-consciousness. It is a matter of being active in a certain way, and the activity is essentially

a reflexive one. This is not exactly because the agent, in guiding his own behavior, necessarily does something to himself. Rather, it is more nearly because he purposefully does something with himself. A person who cares about something is, as it were, invested in it. He identifies himself with what he cares about....He concerns himself with what concerns it, giving particular attention to such things and directing his behavior accordingly. (260)

Frankfurt distinguishes the case of someone who cares only about considerations conducive to moral ends from the usual case of someone who is motivated additionally by a range of non-moral ideals and projects. But even for the rarer former case it is true, he says, that “this person’s moral judgements are one thing and the fact that he cares about them so much is another” (259). In other words, caring motivations dissociate from moral ends. The point, as connected to the current case, is that Dr. B cared about science (and the project) to the extent dictated by his self-image (or role identity), and his role identity motivated him in continuing work in the project. That the project itself is not specifically (or exclusively) morally laudatory is of course beside the point. The central claim is that there is moral self-orientation taking place given that Dr. B is supported in exercising his remaining capacities which include caring about the project. For Sabat to enable this to take place is, as he says, a matter of human dignity.

So Dr. B cared about the project and self-consciously so: its purpose was bound up with his purpose, as a scientist. His self-conception had built into it a certain agential trajectory. Certainly his caring about the role did not directly prod him along (his agency did not involve him doing something *to* himself), but rather the role was such as to orient him in the world as somebody doing something *with* himself, as Frankfurt insightfully expresses it. To have a self-image that is role-centered is to have an image of yourself you imagine performing in various ways. Dr. B’s self-image structured his agency, and it pulled him into a future in which that agency was both a guiding and a governing force. But nevertheless, an explanatory gap remains: Dr. B cannot rely on his episodic memory, so often enough he can’t remember in circumstances what he is supposed to be doing. Yet he does act. More needs to be said.

How is agency possible, then, when the capacity for mental time travel subsides? This capacity for recalling the past and imaginatively rehearsing the future normally supports agency in the sense that plans requiring future mental projections have to be remembered to be effective. It would seem

that the path from plans to action for those with AD is closed. But as mentioned those with AD nevertheless act with purpose, so there must be another means by which this is made to occur, via the self-image which remains. Now the self-image begins with a reflection of the qualities of the person, but it is no mere list. In entertaining a self-image, you present to yourself characteristics fashioned into a story-like account of who you are. "I am Dr. B. I am a scientist. I am working with Steven Sabat on a research project into Alzheimer's Disease. We can get glory." A self-image can be an adaptation of known traits into a form that may articulate with motivation and action itself.¹⁵ The translation from self-image, to story, and then to motivation and action does require something extra though, and though I cannot develop it here, I suggest we look to accounts of habit and the ways habit articulates with normativity.¹⁶ Often enough, our external circumstances generate the cues we need to enact routines with relative automaticity. Nevertheless, such automaticity, though it can get us through, especially when we are not at our best, is not sufficient for full blown agency. Yet, falling back on an understanding of your role in circumstances can provide what is needed to approximate it.

We can learn a lot about the link between narrativity and agency when we consider cases where it goes wrong, specifically cases in which you forget or lose track of your story. (I choose this example for good reason given the connection to AD where memory problems cause people to become disoriented in space and time, and where they lose track of their story.) When the capacity for mental time travel is lost in AD, this leads to frequent problems in the person making sense of (especially) novel situations in which they find themselves. But this occurs also, not uncommonly for those of us without AD—think of cases in which you become distracted say while walking from one room of the house to another, where upon arrival in the room, you've forgotten exactly what it was you were doing. Your agency abruptly ceases because you can't make what you are doing now cohere with what you were doing a minute ago.¹⁷ Nevertheless, you can re-set by thinking about the wider circumstances: what is it you *would* be doing, given your situation or role? Or what is it you *ought* to be doing given these circumstances? Narrative agency can get back on track with reference to your understanding of this wider purpose and role. And if this role is a valued one, especially as testified by those around you, it can add the motivation needed to keep going, especially in the case where there is a danger—given that you have forgotten some specific aspect of the role—of simply giving up.

What was the answer to Dr. B's question "What keeps you going about me"? Sabat says it was about helping and about dignity; but it was also about supporting Dr. B as an agent. By continually providing him with positive interpretations that supported his self-image—by engaging in the process of moral self-orientation—Sabat enabled Dr. B to carry on in his work, to be a scientist, and so to *be* an agent. I suspect Sacks's estimations with respect to Mr. Q apply here, that failure to pay heed to Dr. B's identity might well have hastened his decline. Sabat was keeping Dr. B going in a quite literal sense.

CARE AND THE ESSENTIAL MORAL SELF THESIS

It is important for loved ones and professional carers to understand that losses in episodic memory and language—which may certainly lead to odd self-presentations—do not equate to changes in personhood profound enough to support the stereotypical response to dementia that, as I noted at the start, leads apparently to a 'loss of the self.' This is partly why I think in this context it is important to distinguish between the idea of *person* and the idea of *self*, as discussed earlier. A loss of a remembering self leaves much of the person still intact, including the self-image. In this last section I want to explain why people might erroneously attribute a loss of personhood to someone who displays AD impairments, while simultaneously showing that caring on the basis of assuming the self-image remains intact can in fact provide the social scaffold for it to persist.

I begin by drawing attention to the *essential moral self thesis*, which is that moral traits of personality (even more so than retention of memory) are the "most essential" to ordinary people making judgements about whether their loved ones' identities persist.¹⁸ According to Strohming and Nichols, ordinary people are most swayed in their day-to-day descriptive judgements about personal identity by changes to the moral self. Moral selves are important because of their relevance to "what it means to be human" and how we might "fare as potential partners for cooperation and affiliation" they say (2014, 169). This last point resonates with the thesis of moral self-orientation. If the essential moral self thesis is correct, then it would not be surprising if attributions of continuing identity (or fading identity) are made on the basis of persisting or declining morally saturated character traits. If that is right, it supports a demand for norms that presuppose the process of moral self-orientation. Let me now explain this inference.

In the cases I have discussed, what persists is a person's understanding of, and identification with, a role they occupy or once occupied. The identification with the role confers moral status, and it is this status which is at stake in interpersonal and dialogical contexts, such that a failure to recognize and respect the role would result in a moral loss. If the essential moral self thesis is correct as a general thesis about how ordinary people respond to one another, then it is going to be applied most saliently in social exchanges. It is a commonplace that carers will often say of the person with AD that he or she is no longer the same person as they once knew. Interpreted through the lens of the essential moral self thesis makes it reasonable to believe moral traits play the central role as grounding this familiar claim. It makes it likely that carers who say this believe that the moral self of the person they care for is changed beyond recognition from what it was. This in turn represents a danger for those people with AD who are subject explicitly or implicitly to claims they are no longer the same person. Perhaps they will accept this claim, but if so, they are vulnerable not just to having their feelings injured on some occasion, but in terms of doubts introduced concerning emotions and attitudes about their persisting identity as such. Their identity at this point is constituted mainly from a persisting self-image and not from those other selves that depend on neurotypically-based cognition. Given this, carers bear a responsibility for maintaining as best they can relationships that assume a relatively intact self-image. A self-image is maintained partly through the relations borne to others, relations constituted by the moral self-orienting emotions and attitudes. When caregivers retain principles of respect and understanding, principles which recognize and encourage those roles that structure the identity of those in their care, those in their care are enabled to maintain a continued confidence in who they are, and of their moral standing.

The stance carers may take here extends to quite specific practical approaches. For example, Steven Sabat talks about adopting 'conversational repair,' an approach in which one restates a sentence to a person that at first did not seem to make sense, thereby recognizing the effort to communicate an idea while at the same time taking the trouble to respond to it. This is an approach where empathy (and the respect it presupposes) combines with expertise to facilitate communication and inclusion. Another example where empathy is valuable to carers involves seeing that a person with dementia might behave a little differently out of a rational response to their understanding of how the disease affects them. Thus, here, we have a distinction between behavioural symptoms of the disease compared with

sensible and rational responses *anyone* might make to the challenges they experience with memory or language. For instance, if, having AD, I knew I would stumble with speech every time I tried to converse, I might then stop speaking and exclude myself from social encounters. It might *seem* to others as if Alzheimer's has made me dumb or socially withdrawn (a direct symptom), whereas I might just feel a little ashamed of myself or maybe even a lot, if I previously prided myself on my facility with language.

In these examples, failures to make the effort to communicate or to misinterpret strange behaviour (when it is in fact rational behaviour) have the effect of morally isolating the person, and that just is to exacerbate the damage being done as a result of their AD and to further disorient them in their view of themselves as moral beings.

CONCLUSION

Think of a time you have experienced exclusion, stigma, even ostracism, because of a mistaken belief others have of you, that, for example, you lack some required feature or have a feature that paints you as odd in some way. Such experiences are painful because of their injustice; they leave us anxious, bewildered, and unable to move forward. In the normal run of things social acceptance of who we are is our default, and we expect it to occur. Stigmatized groups such as those with AD enter a social world they already find hard to negotiate because they do find it hard to disguise features such as speaking with fluency, and often enough they know that their strange presentation comes across as odd. The trouble is that others then make a faulty inference from this merely self-stigmatizing behaviour to the mistaken belief that the disease has led to a 'loss of the self.' This, as I have argued, is false on both interpretations of 'self'—either as a particular manifestation of some aspect of the person or as a synonym for the whole person—when the self-image persists. Moral self-orientation continues in this state: social agency and exchange may continue supported by those attitudes and emotions that frame it; the relational self remains disposed for direction and interpretation; the self-image can support normative agency; aspects that are essential to the moral self can still be found. In short, people in this vulnerable condition have remaining abilities that deserve recognition and respect. They are owed, at the very least, the time and space within which those abilities can be found and addressed.

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NOTES

1. My analysis will focus on cases of Alzheimer's dementia, the most common form of dementia. At first the pathology results in losses in the capacity for episodic awareness of times outside the present, with a progressive decay in the sense of subjective continuity. But AD does not, at these stages, destroy semantic memories, leaving functional neural machinery to support a knowledge-based understanding of who a person is, their trait self-knowledge. In Semantic Dementia, the reverse occurs, and patients retain the ability for narrative and self-continuity as this pertains to the recent past but not times more distant. There are other less common dementias I will not discuss. For a comprehensive review of the literature pertaining to the pathological effects on personhood of different dementias at different stages, see Strickwerda-Brown et al. (2019).
2. Agnieszka Jaworska (1999, 15) also discusses the case of Dr. B in the context of the advance directives debate following Dworkin (1993). Her purpose was to show that Dr. B retained the capacity for valuing, which functioned as an internalized directive selecting and rejecting as correct those desires guiding action. As such, they formed a principled framework for his self-governance and so for (a minimal level of) autonomy, leading to an argument resisting Dworkin's conclusion for the authority of pre-dementia advance directives. It is not my purpose here to contribute further to the advance directives debate by focusing on Dr. B's capacity for valuing. My purpose is to focus on Dr. B's continuing self-image, a self that is subject to hurt and reward, which in turn facilitates his moral self-orientation.
3. A concept with wider scope is normative self-orientation, where the values in play need not have specifically moral content, or only moral content. After all, someone can gain a sense of his or her social standing with respect to some normative standard, whatever that may be. One might be aware of coming across as clumsy, a second-rate chess player, or someone who is abrasive in

conversation, while recognizing that these characteristics do not compromise moral standing in any direct way.

4. In emotions such as shame (or self-stigma), the disclosure of self to self with negative valence is a significant problem. As this applies in dementia see Simon Evans (2018) and Martina Zimmerman (2017).
5. Of course the episodic self can be a source of pride or shame when the self in an episodically remembered happening or action brings credit or discredit to the individual now doing the remembering. But who is the “individual now doing the remembering”? Not the episodic self, because that self appears in the content of the episodic memory. The individual doing the remembering *identifies with* that self, as someone (now) proud or ashamed, and since this individual’s self-image shares this pride (or shame), it may source it as well. In the normal case, then, the contents of the episodic self penetrate into the contents of the self-image. In the case of AD, this becomes unavailable and the self-image vulnerable.
6. As I spell out these two aspects of persons, it will become clear that they correspond closely to some familiar distinctions found in philosophy and cognitive psychology. For example, philosophers distinguish between qualitative identity and numerical identity (Parfit 1984, 201–2), between loose and strict identity (Butler 1860, 325), or between characterisation and reidentification (Schechtman 1996, *passim*). Cognitive psychology has been less interested in the philosopher’s sense of a persisting numerically identical self, presumably because of accounts regarded as non-natural or extravagant (e.g., Cartesian accounts), or accounts regarded as un-examinable and transcendent (e.g., Kantian accounts). But they have been interested in the idea of a self-image, as captured by the idea of trait self-knowledge, that is, knowledge we have of our own personalities. (See Nichols (2012) who provides accounts of the philosopher’s ‘thin’ self, compared with the ‘thick’ self of psychology, why ordinary people exploit both selves, and why the former can be ‘functionally beneficial.’)
7. I focus in the present work mainly on the case of AD, involving brain damage and pathology, in which the episodic memory system is disrupted or knocked out, leaving the self-image intact. In addition to these cases there are some relatively rare and remarkable cases of people who *never developed* an episodic memory system. They lack the capacity to mentally travel outside the present moment in order to view themselves, but they have never been diagnosed with a psychopathology, nor have they experienced an accident that has led to this neurological deficit. The case of Susie Mckinnon is like this. As Erika Hayasaki writes, “Mckinnon has no core memories that she

is aware of. But there can be no doubt of her personality....She's bashful and sensitive. Intuitive, curious, and funny. She has a job...hobbies, values, beliefs, opinions, a nucleus of friends. Though she doesn't remember being a part of the anecdotes that shaped her into a person, *she knows very well who she is*" (2016, 4). [my emphasis] Hayasaki notes that Mckinnon (with two others) was the subject of a study in 2015 by Brian Levine and colleagues and since then "hundreds" of people have put themselves forward to his team, though he estimates only a dozen or so from these can be proved to have the episodic memory deficit. (See, for example Palombo et al (2015).) These cases are intrinsically fascinating. They show also that self-presentation and functional agency can be built from largely semantic elements, and in particular they show that a robust self-image may develop unhindered by an absence of the episodic self.

8. The fact that trait self-knowledge updates despite anterograde amnesia is puzzling, and suggests that experience of what one does and of how others react to one is filtered and "interpreted" during periods when working memory operates, and then it "feeds" via implicit learning pathways into trait self-knowledge. But the question regarding the mechanism involved is empirical and not the concern of the present work.
9. I borrow this term from Mograbi, Brown, and Morris (2009), who link the idea of an out-of-date self with the anosognosia accompanying later stages of AD. See also Baird (2019) who discusses the case of a man whose identity was not quite yet petrified, interestingly because of the retention of recognisable moral traits.
10. See https://oer.utas.edu.au/content/enforced/6981-OR-Wicking-UDM_19_02/transcripts/Unit3-LivingWithDementiaACarersPerspectivePart2-Transcript.html?ou=6981. Viewed December 24, 2019.
11. David's case is clear. Nevertheless, I do not claim that moral self-orientation is a process with discrete limitations. Prior to reaching a clear non-case there are significant differences in degree, and these would (in the case of AD) track the progress of the cognitive decline.
12. 'Self' is often used as a synonym for 'person,' but for obvious reasons that would lead to absurdity in the present discussion.
13. See Matthews (2003, 170-171).
14. See Klein, Cosmides, and Costabile (2003, 157) in relation to the resilience point.
15. According to the Social-Cognitive model, social identities generate mechanisms that regulate behaviour, focus attention, interpret situations, and manifest dispositions to respond, once incoherencies in motive and belief are eliminated. (See Aquino and Reed (2002) and Reed and Aquino (2003).)

16. See Peter Railton (2011, 316) who speaks of ‘habitudes,’ those dispositions to “notice features of situations, to feel their force or urgency, to appreciate the values at stake, and to be moved appropriately in thought and action.” For those with AD the retention of such dispositions would articulate with the self-image to bring about recognizably rational agency.
17. Cf. J. David Velleman (1985), who uses the example of losing track of what you’re doing while walking down Fifth Avenue to motivate his view that intentional agency is constituted by conclusions to act derived out of the desire to understand in circumstances what one is doing.
18. See Strohming and Nichols (2014) and (2015). Strohming and Nichols (2015) list honesty, integrity, altruism, justice, mercy, trustworthiness, generosity, loyalty, purity, obedience, decency, duty, gratitude, compassion, and humility as central and important.

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