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**Respecting agency in dementia care: when should truthfulness give way?**

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**STEVE MATTHEWS & JEANETTE KENNETT**

“…When [people with dementia] find themselves in need of facts which are permanently unavailable to them, making it almost impossible to make sense of what is happening in their life, they very reasonably make the best match they can with intact information from long ago. This can result in their own interpretation of current activity being vastly out of sync with other people around them.”[[1]](#endnote-1)

“Much of the time my mother is still very much in touch with reality and remembers events. When confused she still needs to make sense of the world within her altered reality…”[[2]](#endnote-2)

ABSTRACT *Memory loss and other cognitive decline threaten people’s capacities to make sense of the world and their position within it. In Alzheimer’s Disease (AD), such losses occur when the desire to make sense of the experienced world remains. When this desire cannot be satisfied, confusion, agitation, or anger may result. In these situations, a resolution aiming at the truth is not guaranteed to work, and may even exacerbate a difficult situation, since losses to sense-making may damage even the receptivity to it. When the truth is out of reach in this way the aim ought to be instead to create the conditions of proper fit – a fit that is intelligible – between current experience, self-image, and a world that makes sense. We argue that this aim rests on what we call the demand for sense-making, a demand that arises for all of us where respect for agency is at stake, and especially so in AD, when it is under threat.*

**1. Introduction**

Memory loss and other forms of cognitive decline can threaten people’s capacities to make sense of the world and their position within it. In Alzheimer’s Disease (AD), where such losses inevitably occur, the need to make sense of the experienced world remains. When this need is frustrated, confusion, agitation, or anger may result. In these situations, trying to resolve the person’s anxiety or bewilderment by explaining what is really going on – by being truthful – is not guaranteed to work, and may even exacerbate a difficult situation. In such circumstances, carers may engage in forms of deception or ‘going along with’ the person’s out-of-date beliefs to manage the situation and soothe distress.

In 2014 a comprehensive report was prepared by the UK Mental Health Foundation[[3]](#endnote-3) into how we should understand the lived experiences of those with dementia and those who care for them, particularly in relation to the problems presented in being truthful with those in care when they experience ‘…a reality or set of beliefs different from those around them’.[[4]](#endnote-4) The Report seeks an answer to the question about what justifies telling untruths to those with dementia. It offers an appropriately nuanced and layered answer to this question.[[5]](#endnote-5) In this paper our focus will be on one aspect of this justification, that persons with dementia, even quite advanced dementia, face the problem of trying to locate themselves intelligibly within their environment, trying to sort out meaningfully what is going on in that environment and to connect it with their understanding of who they are. This understanding we dub the ‘self-image’. Our use of this term is equivalent to what psychologists call trait self-knowledge, or the self-concept.[[6]](#endnote-6) A person’s self-image is constituted by her understanding of who she is, including her character qualities, likes, dislikes, beliefs, desires, moral judgements, and moral self-evaluations. The self-image of a person with AD typically remains intact, often to a significant degree, throughout periods of memory loss and other cognitive decline.[[7]](#endnote-7) However, those with dementia who retain their self-image often face the problem that it may be out-of-date, and the person may find their surroundings such as to block them from making sense of who they are, given where they are. Nevertheless, they will feel driven to enact aspects of this identity.

When a person with AD is confused, disoriented, frightened or agitated, carer strategies in response, such as looking for an alternative meaning in the confusing experience, or going along with an expressed false, or out-of-date, belief, can be justified by the obligation that we claim sits alongside truthfulness: to help others to make sense of their world. This is required, not just for its own sake, but also to enable and facilitate a level of agency and purpose in the person with AD. Addressing the person’s need and ability to make sense of their environment, which is heightened in the cases of AD we consider, is a requirement of respect for them and for their capacities for agency. While truthfulness is normally required on the grounds of respect for agents, we claim that, since sense-making is a fundamental condition of agency, being less than truthful with someone who has AD in order to allow or facilitate sense-making is also normatively grounded in respect for agency.

We argue that this way of viewing the matter confounds what is normally presented as a dilemma between the fundamental duty to tell the truth to a person with AD, and failing to tell the truth for utilitarian reasons in order to comfort them. The ethical justification we offer for forms of non-truthfulness in care is respectfulness, and though it may be effective in also promoting the well-being of this person (as The Report suggests), this latter justification is not the primary one.[[8]](#endnote-8)

The paper will proceed as follows. We first outline the relevant deficits accompanying AD, and argue that the self-image is retained in spite of these deficits, very often through to the advanced stages. We then present an analysis of why making sense of oneself in circumstances facilitates agency. In the section that follows we identify the kinds of cases relevant to our thesis, cases in which, typically, the self-image can be justifiably supported by non-truthful means. We also discuss the cases representing a limit to the scope of our thesis, cases in which the capacities needed to form a stable self-image have deteriorated too far. In the section that follows we canvass an objection to our theoretical framework which might appear too liberal in the cases it admits. We finish by setting out the principles underlying the stance carers take when responding to people with dementia in accordance with our theory; we call this stance *the default standpoint*.[[9]](#endnote-9)

**2. Alzheimer’s, Cognitive Decline, and the Self-Image**

In this section we identify a key assumption driving our account: that AD leaves the self-image largely intact. This assumption is important, since the demand for sense-making, and the respect it commands, will compete with other norms only if the self-image is left relatively intact throughout the progression of the disease. This is for the simple reason that a person’s self-image needs to be present for things to (potentially) make sense to it, during (say) some period of confusion.

AD is a neurocognitive condition, the most common of the dementias, forming about fifty percent of cases. DSM-5 specifies six cognitive domains affected by AD.[[10]](#endnote-10) These are complex attention, executive function, learning and memory, language, perceptual-motor abilities, and social cognition. AD symptoms are expressed, ultimately, in all of these domains, through an incremental build-up in which the trajectory of the pathology targets certain neurological areas underlying cognitive function. AD, that is, has a typical “narrative” signature in its presentation over time. Importantly for our thesis the domains of social cognition and of skills involving implicit memory – such as music, Tai Chi, walking, dancing, or gardening – are often enough spared even in late middle-stage AD.[[11]](#endnote-11) Social cognition includes my recognition of others’ mental states and emotions, and this includes my capacity to respond to others *as* other persons, like myself. Again, this has cascading effects on behaviour and social understanding. It may include a continued sensitivity to others’ (moral) standing, or the continued ability to morally judge others; recognition of the need to uphold certain standards, adhere to conventions and norms, maintain a degree of empathy, to exhibit moral identity, or to remain oriented in moral space.[[12]](#endnote-12)

Lists of largely functional symptoms provide a profile of disease but typically leave out aspects of the person. It is important to our thesis (as supported by the fact cited above that social cognition remains relatively intact while other domains falter) that the self-image of persons typically persists throughout the progression of the disease, since the demand for sense-making and respect for agency depends on it. So: what happens to the self-image through these changes? It is common in both popular and some medical literature to assume that AD leads relatively quickly to a global deterioration of the self, however, this is not borne out by the evidence.[[13]](#endnote-13) On the contrary there is good reason to think it is sustained close to the end of the progression of the disease. People with AD typically continue to engage in social encounters based on some retained insights into who they are (and were), and their role in a situation, or at the very least an implicitly governed understanding of their social position.[[14]](#endnote-14) Even when episodic remembering for both anterograde and retrograde recall is wholly lost, people may retain the semantic understanding of who they are, that is to say, their self-image persists despite loss of episodic memory function.[[15]](#endnote-15) And indeed, that the capacity for social cognition persists throughout much of the progression of AD suggests that people continue to engage with others on the basis of the retained self-image. This provides an important foundation for the idea that persons with AD retain a capacity and need for sense-making quite close in time to the very latest stages of the disease. Indeed, as our examples show, they retain it even when they experience profound delusions.

**3. Sense-Making, Self-Image, and Agency**

In this section we outline our theoretical position with respect to the way a continuing self-image is important to agency, and of the way sense-making may facilitate the link between them.

Effective human agency depends on the capacity to know what you are doing, both in the moment (synchronic agency) and over time, as when we act now for the sake of some future end (diachronic agency). Sometimes, however, agency is interrupted. Velleman invites us to reflect on the familiar experience of forgetting what we are doing.[[16]](#endnote-16) We walk down the street purposefully but then forget where we were going. What do we do? As Velleman says, we stop. We can’t do anything until we connect our present activity with the goal that originally motivated it. And once recalled, the present activity can then be placed into a narrative sequence that makes sense. In AD the increasing frequency of this kind of forgetting gives rise to increasing hurdles to sense-making, and to placing yourself and your activities in a meaningful sequence.

Sense-making, then, refers to an understanding of what we are doing by seeing the ways in which our acting now has an intelligible fit with what we take to be our circumstances and of who we are both now and into the future. In addition, Velleman suggests that “people are generally guided in their behaviour by a cognitive motive towards self-understanding”.[[17]](#endnote-17) This motive stands behind reflection. It is not a specific desire – like wanting a cup of tea, wanting to take a brisk walk to the shops, or wanting to make dinner – but it provides an important basis for us to discriminate between our various desires since, for example, it may make more sense to go to the shops now while they are open than to have a cup of tea, even if I more strongly desire the cup of tea. What will make sense to us will depend on a range of variables: some will be (merely) situational/context dependent, and some more enduring, having to do with our roles or commitments. Our particular actions are undertaken in accordance with both short-term and longer-term intentions, plans, and desires, and will make sense to us when framed as part of those plans; these in turn articulate with a particular self-image. The self-image grounds and delineates those considerations in the light of which we have reasons to do some things but not others. Perhaps I could be on time, but somewhat dishevelled, to meet you, or I could be late but perfectly groomed. Which I choose may depend on whether punctuality or presentation is more central to my values and self-image. The more central a trait, or role, or value, or activity is to our self-image or identity the more powerful a factor it is in determining our choices and the narrative we weave around them.[[18]](#endnote-18) This provides the link to the cases of interest that motivate our thesis: cases where threats to sense-making impact a person’s agency because a person’s self-image and their environment lack an intelligible fit. There are two variations.

In the first variation, the person *lacks insight* into their AD condition. There are two sub-variations: one where the person does not sense a lack of congruence between self-image and environment, and one where they do. A typical case of the first sub-variation would be one in which a person in an aged care home believes it is their old workplace, and they behave accordingly. The environment provides cues that trigger role-oriented actions. In these cases, the loss of insight means the person does not (subjectively) exhibit signs of confusion – their false beliefs are firmly held, they express them, they act on them, and their agency is (subjectively) effective. A typical case involving the second sub-variation would be one where a person senses that something is wrong: ‘Where am I? What am I doing in this place? Where is my wife? I want to go home now.’ These cases heighten the truth-telling dilemma for carers, and often lies or reassurances are told: ‘Your wife will be here soon, why don’t we sit down and have a cup of tea and wait for her.’ These two sub-variations relate only to a person’s beliefs, or understanding – true or not – in relation to how they apprehend the environment, and as a result are able to make subjective sense of it. The *affective* response to this apprehension is a separate matter. In the first sub-variation above a person may cope very well, with little to no distress, precisely because they are able to negotiate their environment, since it fits with their self-understanding. In the second sub-variation it is common for people to become distressed because their confusion is compounded by the frustrated need to be with a loved one.

In a second variation, a person *retains insight* into their condition, and into the fact that their self-image does not fit intelligibly with the environment, and is periodically (subjectively) confused as a result. Thus, they might as a result become lost while taking a walk, knowing that the disorientation from their AD is the cause, or they might become distressed because of sensory overload during a social occasion, again knowing that it is their dementia which causes them to lose the capacity to make sense of what is occurring in the environment. As one participant from The Report put it:

They [the different realities and beliefs] are frightening. I understand them as an aberration of normal thinking due to brain disease… they are separate to who I am and I cannot use ‘my’ mind during an onslaught…I have to wait for it to take its course.[[19]](#endnote-19)

Our thesis – that respecting the demand for sense-making should sometimes override the demand for truthfulness – gets most purchase in cases of lost insight (the first sub-variation above) in which a person is making sense of their environment in a way that is true-to-themselves, but strictly false. To flesh this out, consider the following actual case. Martha is attending the dayroom with several residents in a dementia care facility.[[20]](#endnote-20) It is the afternoon, and coffee has been served by the staff, who now have returned to the kitchen. Earlier, when Martha and another resident Catherine were sitting in the corridor, some uncertainty had arisen as to who would take care of the arrangements for the coffee. Perhaps they ought to assume some control? As things unfold in the day room, with sociability, and chitchat about the weather, TV, and childhood memories, a change occurs. Martha’s understanding of the situation is transformed. Orulv and Lars-Christer take up the story:

Somewhere along the way [Martha] assumes the status of gracious hostess – a part that has been hers innumerable times throughout her life. Equally innumerable are her stories about how she, like her mother before her, has taken pride in welcoming everyone to her home and in sharing her food and hospitality with other people…These narrative plots occur frequently in the body of material that can be described as variants of one overall storyline that binds together many of Martha’s stories. This storyline is of her being a generous and sharing person throughout her life…[[21]](#endnote-21)

Thus, a previous role-driven self-image – one specifically infused with a moral identity of someone who is ‘gracious’, ‘hospitable’, ‘generous’, ‘sharing’ – emerges to fit with Martha’s current experiences. Martha’s agency is enabled because she is making sense of what is going on in a way that fits with her self-understanding. To intervene here by correcting Martha and reminding her that she is a resident in a care home and not the hostess, poses a risk to her identity and agency. Its effect would likely be to confuse Martha and bring what she took herself to be doing to an abrupt halt.

If this is right, the demand for truthfulness in dementia would potentially disturb a sense-making process that is *prima facie* good for people – one that provides narrative continuity and allows the person, at least temporarily, to act effectively in line with their self-image. In this range of cases – of lost insight without disturbance – agency may be blocked if a person is prevented from matching their self-understanding with the circumstances. Since Martha can make sense of her circumstances in this way, and since this agency reflects something of who she is (and was), carers may, and indeed ought, to respect her intentions in playing the role of hostess.[[22]](#endnote-22)

The capacity for sense-making is separate from the affective drive we have towards it. People who develop AD typically retain this affective drive, even when their sense-making capacities have deteriorated considerably. The agential drive remains even when the capacity for meaningful engagement with the social world is failing, and such cases indicate the moral limits of our thesis. Consider here the case of Dr. M discussed by Oliver Sacks.[[23]](#endnote-23) Dr. M had been the medical director of a hospital where Sacks had worked, he then retired in his 70s, later developing AD and vascular dementia. Given his familiarity with the layout of the hospital where he had once worked it was decided he should reside there. Dr. M at this point had a relatively advanced dementia – he was confused, disoriented, and often agitated and distressed. These latter features appear exacerbated by, indeed largely explained by, Dr. M’s drive to agency which was constantly thwarted by his failure to fit his self-understanding with his situation. From time to time he believed he was still a doctor there, and acted out this role. What is striking from Sacks’s description is Dr. M’s drive:

The first weeks and months here were exceedingly difficult. Dr. M. showed incessant “drive” and agitation, and was put on phenothiazines and Haldol to calm him… With the cessation of such drugs, he has regained his physical health and energy—walks and talks freely, but requires constant attendance (for he would wander off, and is erratic and unpredictable in the extreme)… unhappily, he is driven and distraught for [much of the time]… Sometimes he fails to recognize Dr. Schwartz, sometimes he fondly calls him “Walter.” And I had a very similar experience this morning: when he was brought into [my office], he was very agitated and driven, would not sit down, let me talk with him [or] examine him. A few minutes later, by chance, when I passed him in the corridor, he instantly recognized me (having forgotten, I think, that he had seen me a few minutes before), called me by name, said, “He’s the best,” and asked me to help him.[[24]](#endnote-24)

Dr. M’s drive – his energetic urge to act in the world – is frustrated when he doesn’t understand what he is doing, for the urge is given nowhere to sit in a narrative that combines self-image with current experience. For Dr. M, sustained sense-making that can support a role seems out of reach because it is too fleeting. There are only moments of (seeming) clarity, such as the last in the quote above, where he briefly recognises who Sacks is, and responds with some sense and poise. There were even short episodes – islands of narrative connectedness to a past – where he might act with intelligibility. Sacks says:

At such moments, when Dr. M. stepped into his prior role as a hospital director, the transformation was amazingly complete, even if brief. It happened so quickly that none of us quite knew how to react, how to handle this unprecedented situation. But these were rare interludes in his frenzied, driven life.[[25]](#endnote-25)

Dr. M retains a self-image that is time-shifted back a decade, but its expression fluctuates radically, and without such stability and unification, others around him cannot mirror back to him persisting feedback that might reinforce a sense of who he is over sufficient time. It is those (epistemic) cognitive domains that might support this possibility that are under threat here. He has plenty of drive but nowhere he can consistently put it. He represents a case where the conditions for scaffolded agency may be out of reach, and that is because sense-making strategies in which a carer goes along with what is said and done depend on a degree of consistency of character over time. In these cases, careful attention to situational changes is called for to address the potential for distress. In particular, a sensitivity to what the person may encounter in their environment is the overriding consideration. Sacks mentions an incident in which Dr. M accidentally read his own chart, to devastating effect. As he described it:

On one occasion, [Dr. M] saw his own chart, said “Charles M.—that’s me,” opened it, saw “Alzheimer’s disease,” and said, “God help me!” and wept.[[26]](#endnote-26)

Cases like this where insight fluctuates pose the most troubling of problems because whichever stance a carer takes towards the person is often quickly knocked off balance. In another case of this type a carer described her husband David in the following terms:

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.[[27]](#endnote-27)

In such cases, where there is an insufficiently stable self-image, the normative demand to support sense-making (grounded in the respect for agency) begins to lose its grip because by this point a person’s capacities for recognisable agency itself are too diminished. As well as mixed insight cases, there are cases in which the dementia is so severe the person is simply unable to piece together the fragmentary mental items in experience and weave them into a meaningful form, and this may be exacerbated by late onset psychoses or delirium. All such cases, where sense-making is beyond the reach of the person, represent a limit on the scope of our thesis.

**4. An Objection to our Framework**

On our view, truthfulness in care may be suspended when the competing principle is respect for the agency of a person. Our paradigm for motivating the position are the cases of past identities, particularly role identities, which may be cue-triggered in circumstances, in a relatively stable form, thus enabling the person to make sense of those circumstances given their self-understanding as occupying the relevant role. But what about other cases in which people take on very different role identities, say a child pretending to be movie character, or a floridly delusional individual who thinks they are Superman, or the son of God? Does our framework of respect for agency as support for sense-making require “going along with” these identities? If not, what distinguishes the cases?

In order to respond to this, while further refining our theory, we will focus on two examples of role identity case (we call these Type-1 cases): (a) the case of a child engaged in pretend play (say, that she is Wonderwoman), and (b) the case of a person experiencing a florid identity delusion, e.g., a belief that he is Jesus Christ. Our first challenge is to explain why our framework should not apply in these cases. As might be expected we will argue that there is a difference between respecting agency connected to who the person really is (or was), and on the other hand respecting agency connected to a fictitious or delusional sense of self. However, though we think this move in the argument will head off the non-AD cases, it remains problematic, since there are AD cases of people who form identity delusions that are unrelated to who they are or were. We call these Type-2 cases. Should carers *respect* these agencies and beliefs, or should their response be grounded in a well-being account?[[28]](#endnote-28)

We begin our response with a consideration of Type-1 Cases, where we need to explain why respecting the sense-making demand applies in the cases of AD we address, but not other kinds of cases. First, consider the pretend play cases. Children pretend to be all kinds of characters: superheros, fairies, famous sports people, builders, doctors, and so on. The objection might be: if I go along with my child’s playacting that she is a superhero, is this respectful of her agency and of her personhood?

Our reply is that going along with a child’s playacting is indeed respectful of their agency but this differs from the AD cases because what is at stake here is the question of childhood development, and pretend play is well-known to provide support for it.[[29]](#endnote-29) But before we explain the difference, we should again emphasise that when the demand for sense-making arises, insight may be present or not, and the person may be agitated or not. In these cases, the child is not distressed by the role they are playing – quite the opposite, they are motivated to play the role, and act out its prescriptions, say to save the world, or to right great wrongs and so on. And children engaged in pretend play of course do not really believe they are the characters they are playing; they do not, for example, jump off buildings thinking they have the powers of flight. So, given this insight and relative composure, in fact we do go along with such pretend play as a way for children to explore their world by *trying on* various roles. It might be a TV character, or a professional role, or a cartoon character role. In pretending to be someone else the child exercises their power of imagination, so to *not* go along with the child playing such characters would in fact be to squash their agency, to undermine an important part of development. This is respect for agency, but not *really* a respect grounded in the demand for sense-making, but rather grounded in the important role parents and guardians have in development. To see further the contrast, it would be *disrespectful* to go along with a parent with AD who thought *she* was Wonderwoman; it would be patronizing, demeaning, perhaps infantilizing. And though some parents discourage their children’s beliefs in the myths of Santa, fairies, and so on, in a case where a child said they were a builder, about to build a castle, to insist the child was not a builder, but a mere child playing with blocks, would be extraordinary – it would misunderstand what was really at stake.

Consider now the second example of cases of florid identity delusions related to mental illness. In these cases, the person lacks insight, holding beliefs (or inhabiting a reality) profoundly different from those around them. They may believe they are a fictional or religious figure (such as Jesus). Should carers go along with this, should they respect this kind of agency?

Cases of (especially) imminent harm aside, the question raised against us concerns whether respectfulness is the correct attitude for carers. We reply first by distinguishing between the idea of respecting the agency of the person as they were (or are), and respecting *some* agency (whatever it may be). In the cases we identify, carers have the chance to respect the agency of the person themselves, the retained self-image. Martha really was a person who took on the role of hostess in a serious way, and its reprisal at morning coffee had both a narrative and normative fit with her past. It was her agency, not merely *some* agency.

In cases of florid identity delusions, this feature of owned agency is absent. To respect merely some agency, is not respectful of the whole person, their history, and personality, and who they are, as understood by their family and community. (And to emphasise, these cases are not like pretend play cases in which insight is retained, and what is stake is the development of the child’s agency.)

Nevertheless, a person with a florid delusion is still driven to act on the basis of making their world intelligible, in order to connect their belief about a role with their circumstances. Thus, a person with an identity delusion, say someone who believes he is Jesus Christ, may have a continuing sense that he is Jesus Christ, with accompanying episodic memories and future plans. The Jesus identity becomes enmeshed with their own. Consider the case of Craig Hamilton who formed such a delusion, and then wrote about it.[[30]](#endnote-30) Just prior to leaving for the Sydney Olympic Games (in his role as sports journalist), Hamilton was hospitalized. He later wrote,

*In my mind I had become Jesus Christ reincarnate*…The Jesus notion hadn’t struck me like a lightning bolt but, rather, taken shape as a result of an escalating mania throwing off grandiose delusions…All the events of my life to that point had been readying me for this occasion, or so I thought. In the two days before arriving at the railway station my Olympics planning had changed. I had a new assignment. It was perfectly clear: I was going to change the world. My gospel for the global audience was disarm, feed the hungry and love one another.

We are not suggesting that carers, or hospital staff, encourage the person to persist in their delusional beliefs; however, the case points up again the centrality to agency of trying to make the world intelligible, given one’s identity beliefs and circumstances. Hamilton’s anomalous, mania-driven, experiences of the world and of himself, resulted in the formation of an identity belief that might in part be understood as satisfying the need for intelligibility. That he is Jesus explains everything to him![[31]](#endnote-31) So, what does respect for agency require of us in such cases? In practice there is a division on therapeutic approaches to delusional beliefs: sometimes the best approach is truthfulness and to challenge the person; sometimes this is not the best approach, and neither disputing nor reinforcing the identity is best. In many cases truthfulness would simply fail – Hamilton reported that it took more than a week before his delusion began to subside. So, our claim is not so much that carers respect and support the Jesus-based aspects of Hamilton’s identity and agency, but that they understand and respect Hamilton’s need for sense-making in the context of the delusion, rather than seeing the delusional content as utterly unintelligible. The underlying pathological causes then become relevant and may need to be addressed with pharmacotherapy to bring the person’s beliefs back into alignment with their true circumstances. In cases of delusion where such a realignment is possible, such as in bipolar disorder, that is the appropriate goal. It is not in conflict with respect for the sense-making efforts of those suffering delusions, and this therapeutic approach also mandates a patient, open-minded and charitable attitude to what the person is saying about themselves. But we claim that in cases where recovery is the goal, support for sense-making does not in general require us to set aside the demands of truth and go along with, or provide support for, the delusional content. Here respect for the diachronic agency of the patient may take precedence over situational sense-making in accordance with the delusion. Our point here is that what respect for sense-making requires is context-sensitive, and so a reversible delusional identity requires a different approach to a fixed out-of-date identity.

Hamilton’s hospitalization was distressing for him, given his project to rid the world of war and famine, and his belief that, as Jesus incarnate, he might be effective. Frustrating his agency, as necessary as that was, had its cost. This raises the prospect that there might be cases of identity delusions had by people with AD where, even if such identities were never had by the person in the past, enacting such identities might provide some local sense-making fulfilment and which might be harmless. We now consider those cases.

In Type-2 cases, then, the sense-making demand is present but the person with AD comes to enact a role they have never had. A person might think they are a performer (an actor, a singer, say) when they never were. What do we say here? These cases are like the case of Martha but without the history, and without the clear connection to the self-image of the person in the past. In our paradigm cases a person reoccupies an identity from their past and uses it to guide their actions, but in these cases the person adopts a role that was never their role. Such cases may appear to be like the child engaging in pretend play, but we don’t think they are. Something else is going on.

The first requirement of respect for sense-making may be to try to answer the question “Why this role or identity?”. Perhaps the person was a keen fan of the famous singer they now believe they are. They read all the biographies, bought all the records, went to the shows, fantasized about being friends, and about conversations they would have. And now they have lost the capacity to mark the boundary between themselves and their idol. Or perhaps they had a secret ambition that circumstances meant they could never pursue. It is conceivable that the fictive identity does reveal and express something of who they are. As for the more usual case, inquiry into the past is crucial and may lead to the judgement that the new role-based agency should be supported.

In Type-2 cases the utilitarian argument for going along with the person is that the alternative may be distressing to them. We certainly agree with that, but we think also there is a case for saying that such local identities deserve our respect as well: insofar as they may express an aspect of the person and allow them to organise their actions and make sense of their environment.

We finish this section to explain why we think respect for the sense-making demand in agency does not always apply, *regardless* of the type of case. There are certain kinds of self-image – the violent criminal say – that do not deserve our respect, certain agencies for which deference and acknowledgement would be anathema, and when these are manifested in a person with AD no obligation accrues to the carer.[[32]](#endnote-32) We state this as a purely normative constraint related to the nature of the role, or identity, that a carer may encounter, and the thought is that carers ought not be required to respect what can’t be respected.[[33]](#endnote-33) What if, for example, the (former) identity of a person in care was a crime boss? Or a serial abuser in relationships? Or perhaps the person occupied a senior role in armed services that were responsible for systematic abuses – perhaps the person remains proud of that role, speaks about it, and so on.[[34]](#endnote-34) In such cases non-truthful sense-making carer practice would turn out to tolerate a repugnant agency. Our view, when applied, works best when a relationship forms between the carer and cared, and when respect goes both ways. Carers ought not be required to respect morally repellent or loathsome individuals.

**5. The Default Standpoint**

What is at stake in this debate is the preservation of respect for agency in AD when agential capacity is diminished. The capacity for sense-making normally underwrites such respect and so when it begins to falter, and we cease to know where we are in the world or what we are doing an attitude of beneficence may replace respect in care situations. On the position we advocate, a recognition of the remaining capacity to find meaning in one’s situation assumes centre stage, and this thesis has implications for the stance carers ought to take in their role. In this section we outline the implications of our position for the stance carers can take which we call the *Default Standpoint*.

People with AD retain many of their pre-morbid abilities, traits, role identities, and especially the internalized normative self-understandings that orient them in social settings. This last feature is connected to the first three: a person may come to remember/understand who they are, including what they can do, or what role they may play (including the values and interests that role brings to a situation) only when the social situation allows or triggers an aspect of their identity. Martha plays hostess at morning tea for precisely this reason. These are retained features, remaining qualities, past identities that the disease has spared. In a remarkable case of music therapy (made popular by the documentary *Alive Inside*) a man called Henry, normally mute and unable to communicate, is brought back to social awareness upon hearing music from his past.[[35]](#endnote-35) Henry transforms from being unable to recognize his own daughter to a state in which he is able to converse with his family and carers. He is able to answer questions about his past, the music that animates him, and what it means to him. He becomes re-acquainted with a core part of his remaining self-image, something central to who he was in the past, and responds accordingly.

The default standpoint enjoins practitioners to come to an understanding of the person, their history and personality, precisely to equip them to assist the person in linking their present with their past and to facilitate the drive to sense-making that is fundamental to agency. When carers practice under the default standpoint it is respect for the person as a diachronic being that underlies their motives. They see the individual in care as a whole person, and worthy of engagement on that basis – even if this person reprises a role from the past that doesn’t quite fit current circumstances. This stance of respectful engagement contrasts with the motivations that emerge from the standpoint of treating the person in care as merely someone to be managed in such a way as to reduce their discomfort, or promote (narrowly conceived) well-being, that is, well-being that is about physical or psychological comfort synchronically understood. To be clear, we are not arguing that the well-being of persons is not of great importance. When a carer is motivated by the demand for sense-making and respect for agency they will be inclined to facilitate it by finding out something about the person. Henry’s favourite music from his earlier years had to be played to him in order to bring him back to a semblance of social agency, and once in that state his self-presentation visibly changed from a dour, disconnected, and withdrawn individual to someone happy, engaged, and able to articulate a view on what the music meant to him, both then, and back when he was young. Thus, the key to improving his well-being, in the most meaningful way, was to *begin* with a diachronic understanding of the person, something requiring a respectful effort to find out something about him.[[36]](#endnote-36)

Our claim that sense-making and respect for agency ground a competing norm to the standard utilitarian one is not monolithic: it is clear that in certain emergency situations the lying option is motivated primarily to avoid harm.[[37]](#endnote-37) The claim is that the moral justification we offer in terms of helping a person make sense of their world should be both the default and the fundamental rationale that underpins practice. Under this model a carer needs to know something about the person they are caring for – something about who that person is, in particular their history, personality, interests, values, roles, sensitivities and so on; the more that can be known the better. Being equipped with this understanding brings to the surface a recognition of who the person is, and best enables a carer to provide the conditions under which that person can make sense of things. It is a way of “rescuing” what remains of someone’s personality and agency, a way to access it, to engage it, and to bring the person back into the social world as a participant within it.

On the theoretical account we offer, then, consequentialist justifications that are standardly put forward for non-truthfulness, including the need to reduce the potential for harm, to maintain calm, or more generally to facilitate ongoing good relations between care workers and residents are important, but not fundamental. What is morally fundamental is the requirement to respect a person whose agency is threatened by their inability to make sense of themselves and their social world. We emphasise that the demand for truthfulness ought to be our priority – this is central in the default standpoint; it is given up only in situations where the competing norm of sense-making we identify trumps the requirement for truthfulness. We don’t make a claim about what the threshold might be in a situation that permits non-truthfulness; indeed, our hunch is that it is practically unworkable to provide fixed or rigid guidelines that would smoothly determine when to stop being truthful and to prioritise sense-making. Partly this is because being truthful in general does already respect sense-making and agency, and it is only after persistent failures of the sense-making capacity that the default standpoint might allow for another (non-truthful) approach.

**6. Conclusion**

Respect for agency, and its manifestation in the drive to make sense of what we are doing ought to be our default in the cases of dementia care where truth-telling is an issue. This is not to say that relieving distress or attending to the well-being of a person does not count, and indeed in the cases we considered it is generally true that in so far as persons with dementia are able to (subjectively) make sense of a situation or act out a role, this narrative connectedness between self and situation provides them with a place in the world and resulting sense of composure. When the norm of respect for agency is understood in terms of the drive for sense-making carers will be motivated to discover, especially from family and friends, information about the history and personality of the person in order to place themselves in best position to respond to this demand.

Within the default standpoint initially odd behaviour as displayed in our cases prompts enquiry as to why it is taking place – what is it about this person’s past that gives rise to this behaviour? What is it about this person? Straightaway the object of moral concern is the person and the agency, and not (just) the unsettling behaviour. The response from carers can then focus on a different object, the remaining qualities of the agent. The response seeks to find out something about this person, as the ground for what comes next. Carers so motivated would defer to this demand by seeing it as falling out of a principle of respect for, and recognition of, who a person is. The consideration grounding such motivation forms the basis of a *principled* stance in practice, and so something systematic by which carers may decide when truth should give way, for the sake of agency. This forms the moral core of the default standpoint.

*Steve Matthews, Plunkett Centre for Ethics, Australian Catholic University, Melbourne, VIC. Australia. Stephen.matthews@acu.edu.au*

*Jeanette Kennett, Centre for Agency Values and Ethics, Department of Philosophy, Macquarie University, Sydney NSW 2109, Australia, Jeanette.kennett@mq.edu.au*

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1. NOTES

   Alise Kirtley & Toby Williamson [a]. *Dementia Truth Inquiry: Review of evidence. A supplement to the report “What is Truth: An Inquiry about Truth and Lying in Dementia Care.* (London: Mental Health Foundation, 2016), p. 64.<https://www.mentalhealth.org.uk/sites/default/files/dementia-truth-enquiry-roe_0.pdf> [accessed, Sept 21, 2020]. We refer to this publication throughout as the Report Supplement. [↑](#endnote-ref-1)
2. Kirtley & Williamson [a] op. cit., p. 47. [↑](#endnote-ref-2)
3. Alise Kirtley & Toby Williamson [b]. *“What is Truth: An Inquiry about Truth and Lying in Dementia Care.* (London: Mental Health Foundation, 2016). <https://www.mentalhealth.org.uk/sites/default/files/dementia-truth-inquiry-report.pdf> [accessed, Sept 21, 2020]. We refer to this publication throughout as The Report. [↑](#endnote-ref-3)
4. Kirtley & Williamson [a] op. cit., p. 4. [↑](#endnote-ref-4)
5. The Report was based on a related inquiry centred around a panel of twenty-one people with experience and expertise in dementia, including people with dementia, carers (paid and family/friend carers), professionals and academics. The panel met ten times, during which a range of invited expert witnesses were called, including professionals in dementia care, researchers, frontline practitioners, artists, and police. The Report also used a comprehensive literature review, as well as a wide-ranging public online survey, and consultation groups. [↑](#endnote-ref-5)
6. See for example: Jason Mitchell, ‘Social psychology as a natural kind’, *Trends in Cognitive Sciences,* 13, (2009): 246-51. [↑](#endnote-ref-6)
7. See for example: Stanley Klein, Leda Cosmides & Kristi Costabile, ‘Preserved knowledge of self in a case of Alzheimer’s dementia’, *Social Cognition*, 21, (2003): 157-165. [↑](#endnote-ref-7)
8. The standard justification for lying is relief of distress or agitation. See, for example: Ian James, Amy Wood-Mitchell, Anna Waterworth, Lorna Mackenzie & Joanna Cunningham, ‘Lying to People with Dementia: developing ethical Guidelines for Care Settings’, *International Journal of Geriatric Psychiatry*, 21, (2006): 800-801; Lorna MacKenzie, Karin Smith & Ian James, ‘How a time machine concept aids dementia care’, *Nursing Times,* 111, 17, (2015): 18-19; Ruth Elvish, Ian James & Derek Milne, ‘Lying in Dementia Care: an example of a culture that deceives in people’s best interests’, *Aging and Mental Health*, 14, 3, (2010): 255-262; Maartjue Schermer, ‘Nothing but the truth? On truth and deception in dementia care’, *Bioethics,* 21, (2007): 13-22. [↑](#endnote-ref-8)
9. The term ‘carer’ is sometimes restricted to family and friends of those with dementia; unless the distinction will matter for specific points, we will use it more generally to include paid staff within aged care residences, including professional staff. [↑](#endnote-ref-9)
10. American Psychiatric Association. DSM-5. (Washington DC: American Psychiatric Publishing: 2013), p.611. [↑](#endnote-ref-10)
11. On social cognition, see DSM-5, p. 612. In relation to skills (using music as an example), see Melissa Leggien, Michael Thaut, Luis Fornazzan, Tom Schweizer, Joseph Berfett, David Munoz & Corinne Fischer, ‘Music Intervention Approaches for Alzheimer’s Disease: A Review of the Literature’, *Frontiers in Neuroscience*, 13, (2019): 132. [↑](#endnote-ref-11)
12. Steve Matthews, Moral self-orientation in Alzheimer’s Dementia’, *Kennedy Institute of Ethics Journal*, 30, 2, (2020): 141-166. [↑](#endnote-ref-12)
13. For presentation of this evidence, see for example: Ruth Tappen, Christine Williams, Sarah Fishman & Theris Touhy, ‘Persistence of self in advanced Alzheimer’s Disease’, *The Journal of Nursing Scholarship*, 31, 2, (1999): 121-125; Rakel Berenbaum, Chariklia Tziraki & Keren Mazuz, ‘The Enduring self: personhood, autonomy and compassion in the context of community-based dementia daycare centers’, *Journal of Compassionate Health Care*, 4, 8, (2017): 1-10; Astrid Norberg ‘Sense of self among persons with advanced dementia’, In Thomas Wisniewski (ed.) *Alzheimer’s Disease* (Brisbane: Codon, 2019), pp. 208-209; Sam Fazio & David B. Mitchell ‘Persistence of self in individuals with Alzheimer’s Disease: evidence from language and visual recognition’, *Dementia*, 8, 1, (2009): 39-59; Tippett Lynette J., Prebble Sally C., Addis Donna Rose. ‘The Persistence of the Self over Time in Mild Cognitive Impairment and Alzheimer's Disease’, *Frontiers in Psychology*, 9, 94 (2018), DOI=10.3389/fpsyg.2018.00094. [↑](#endnote-ref-13)
14. Matthews, op. cit. [↑](#endnote-ref-14)
15. See, for example, Klein et al op. cit; Cherie Strickwerda-Brown, Matthew Grill, Jessica Andrews-Hanna & Muireann Irish, Muireann, ‘All is not lost – rethinking the nature of memory and the self in dementia’, *Aging Research Reviews*, 54, (2019): 1-11. [↑](#endnote-ref-15)
16. David Velleman, ‘Practical Reflection’, *The Philosophical Review*, 94, (1985): 33-61, p.33. Psychologists have studied this phenomenon – sometimes dubbed (misleadingly) the *doorway effect* – and a small literature has emerged around a set of issues concerning the way changes in context have effects on short term memory retention. See for example Gabriel A Radvansky, Sabine A Krawietz, and Andrea K Tampkin, ‘Walking through doorways causes forgetting: further explorations’, *Quarterly Journal of Experimental Psychology*, 64, (2011): 1632-1645. [↑](#endnote-ref-16)
17. David Velleman, *Self to self* (Cambridge: Cambridge University Press, 2006), p. 8. [↑](#endnote-ref-17)
18. This is usefully comparable to the Social-Cognitive theory in which agency is determined partly through the filter of an understanding of one’s social identity, and where cognitive processes which focus our attention, assemble meaning from context, eliminate incoherencies in representations of situation, then feed into dispositions to behave. See, for example: Karl Aquino & Americus Reed, ‘The Self-Importance of Moral Identity’, *Journal of Personality and Social Psychology,* 83, 6, (2002): 1423–40; Americus Reed & Karl Aquino, ‘Moral Identity and the Expanding Circle of Moral Regard toward Out-Groups’, *Journal of Personality and Social Psychology,* 84, 6, (2003): 1270–86. [↑](#endnote-ref-18)
19. Kirtley & Williamson [b] op. cit., p. 38. [↑](#endnote-ref-19)
20. This case is described in Linda Orulv & Lars-Christer Hydén, ‘Confabulation: sense-making, self-making and world-making in dementia’, *Discourse Studies*, 8, 5 (2006): 647-673. [↑](#endnote-ref-20)
21. Ibid, pp. 655-66. [↑](#endnote-ref-21)
22. The UK Report Supplement (Kirtley & Williamson [a] op. cit., p 65) describe another case of a woman who believed her care home was a hospital obstetrics and gynecology department in which she saw herself as continuing her work as a midwife. In another case described by Oliver Sacks a man with AD he called Mr Q (a former janitor) took up this “role” within his care home (as supported by the staff there); see, Oliver Sacks, ‘How much a dementia patient needs to know: should a doctor replace an accustomed identity with a meaningless “reality”?’, *The New Yorker* (March 4, 2019). <https://www.newyorker.com/magazine/2019/03/04/how-much-a-dementia-patient-needs-to-know> [accessed Sept 15, 2020]. [↑](#endnote-ref-22)
23. Sacks op. cit. [↑](#endnote-ref-23)
24. Ibid, p. 4. [↑](#endnote-ref-24)
25. Ibid, p. 4 [↑](#endnote-ref-25)
26. Ibid, p. 4 [↑](#endnote-ref-26)
27. As described by David’s carer in an interview available within *Understanding Dementia*, a MOOC offered by the The Wicking Institute at the University of Tasmania, See <https://www.utas.edu.au/wicking/understanding-dementia> [accessed March, 2019]. [↑](#endnote-ref-27)
28. We thank a referee for raising the problems associated with both types of case and presenting the objection as described; we also thank another referee for raising the objection associated with the AD cases. [↑](#endnote-ref-28)
29. There is now a significant literature on the role of pretend play in children’s development, where it is thought to provide a grounding for, especially cognitive competencies of various sorts, including abstract thinking, perpective-taking, and communication. See Doris Bergen, ‘The Role of Pretend Play in Children’s Cognitive Development’, *Early Childhood Research and Practice*, 4 (1), n1, (2002): 1-13; see also Angeline Lillard, Ashley M. Pinkham, and Eric Smith, ‘Pretend Play and Cognitive Development’ in U Goswami (ed.), *The Wiley Blackwell Handbook of Childhood Cognitive Development*, (UK: Wiley-Blackwell, 2010), pp. 285-311. [↑](#endnote-ref-29)
30. Craig Hamilton, *Broken Open* (Sydney: Bantam, 2005), p2. [↑](#endnote-ref-30)
31. For an enlightening discussion of these issues see Sofia Jeppsson, ‘Psychosis and Intelligibility’, *Philosophy, Psychiatry & Psychology*, forthcoming. [↑](#endnote-ref-31)
32. We thank a referee for urging us to address this point with more force. [↑](#endnote-ref-32)
33. In the main text we offer some paradigm cases we think are beyond dispute; but we certainly agree there are borderline cases. A principled stand will depend on one’s background (first order) normative theory. Kantians will diverge from their utilitarian or teleological cousins. [↑](#endnote-ref-33)
34. For discussion of such a case see, Mark Sinyor ‘My Patient the Nazi’, *Canadian Medical Association Journal*, 181, 8, (2009): 502-503. It is (perhaps) rarer to find cases of a reprised role that is repugnant in this way because care settings cue-trigger roles in quite specific ways – consider those from above where the care home, or activity within it, must closely mimic a past environment. Being a crime boss, for example, might be too general, and the care home too unlike the kinds of settings that would trigger someone into behaving that way. Nevertheless, there remain problematic dispositions for those with forensic histories. See for example: Jeong-Min Kim, Kon Chu, Jung Keun-Hwa Lee Soon-Tae & Lee Sang-Kun, ‘Criminal manifestations of dementia patients: report from the national forensic hospital’, *Dementia and Geriatric Cognitive Disorders Extra*, 1, 1, (2011): 433-438; Catherine Lewis, Cynthia Fields & Elizabeth Rainey, ‘A Study of geriatric forensic evaluees: who are the violent elderly?, *Journal of the American Academy of Psychiatry and the Law*, 34, (2006): 324-332. [↑](#endnote-ref-34)
35. *Alive Inside* can be viewed here: http://www.youtube.com/watch?v=an\_npmy. [↑](#endnote-ref-35)
36. We thank an anonymous referee here. Respecting agency via knowledge of the person and a concern for their well-being go together in ways we previously had overlooked. [↑](#endnote-ref-36)
37. A standard example often given is one in which a highly distressed person with AD is trying to force their way from a residence because they falsely believe they must attend to the needs of a spouse, who in fact has been dead for many years. Lying to this person – for example, claiming that the spouse has just phoned and is at home and does not require their help – may be the least bad solution in such a case. See, for example: Kirtley & Williamson [b] op. cit., p 35. [↑](#endnote-ref-37)