

THE SPIRITED INTERWORLD: CAREGIVING AND THE LIMINAL PHENOMENOLOGY OF DEMENTIA¹

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I. KINDRED SPIRITS

In the later stages of my mother's decline from Parkinson's disease, she would occasionally look at me across the room, smile shyly, and ask me if we were alone. There was vulnerability in her asking. She was aware of her dementia diagnosis and was tracking her own cognitive decline to the extent that she could, which meant that she was contending not only with the cognitive distortions that dementia necessarily brings, but also with fear and embarrassment that made her reluctant to communicate with others about her experience. As a part-time caregiver to my mother during the last years of her life, I knew that it took courage for mom to ask me if we were alone, and I knew why she was asking.

In my view, there was seldom anyone in the room save for my mother, myself, and a sleeping cat. Mom's perceptual reality, however, was different. As her Parkinson's disease progressed, my mother developed dementia with both visual and auditory hallucinations, clinically referred to as Parkinsonian psychosis, which affects about forty percent of those with Parkinson's in the later stages of disease progression.² Protracted visual and acoustic

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² The numbers vary widely, in part because not all symptoms of Parkinsonian psychosis are reported. Parkinson's is a degenerative neurological disease, and Parkinsonian psychosis is best understood as a hybrid neuro-psychiatric condition wherein mental health symptoms are caused by neurological

hallucinations were common during the last year of her life.³ At times, the hallucinations were of people she knew: me, my brother, my late father, her siblings, parents, friends, and acquaintances. At other times, the hallucinations were complete strangers. Not all the hallucinations were human; a menagerie of animals often kept her company.⁴ Whether they were foreign or familiar, mom referred to the hallucinations as “the spirits” and interacted with them freely. Across the arc of her illness, the spirits were for the most part a banal and even benevolent presence. She became attached to them. If I suggested we go out for a walk, reluctant to part with their company, she might become alarmed at the thought of leaving them behind. Once, on the way to the doctor, she started talking to one of the spirits, who (unbeknownst to me) was apparently tagging along in the back seat of the car. Often she would speak or emote in a way that made it clear that she was interacting with spirits who remained imperceptible to me. When I would tuck her into bed at night, she would occasionally look up at me and smile. “Thank you all very much,” she said more than once, even though, in my view, I was the only other person in the room.

Mom’s life began to unfold to a soundtrack that was inaudible to me. She would occasionally ask me to turn off the radio when the radio was not on. I would see her tapping her foot and ask her what music she heard. “We love this tune,” she’d answer with me never quite knowing who this “we” was. Sometimes she was unable to hear me above the din of the spirit-crowd; she was often distracted by perceptions that I could neither discern nor name. From my perspective, it seemed that my mother and the spirits were in cahoots. She might become frustrated when she asked something of them and they wouldn’t oblige. For instance, she complained that the spirits left the lights on all night, or turned the television volume up too high, and watched too late into the evening, refusing her requests for peace and quiet. But for the most part, at least until the very last stage of the disease, mom’s communion with the hallucinations was peaceful. It was only in the very last weeks of her life that the hallucinations progressed into delusions, understood as more thoroughgoing and fixed belief systems or worldviews, often paranoid or persecutory.⁵

pathologies in the brain, specifically declining levels of dopamine. Hallucinations are actually the side-effect of medications prescribed to increase dopamine levels in the brain in order to alleviate the motor symptoms of the disease. This is particularly the case with Carbidopa/Levidopa (L-DOPA), the current standard-of-care pharmaceutical. L-DOPA can dramatically improve the motor symptoms of Parkinson’s disease, but the drug also affects biochemical changes in the brain that can cause hallucinations and delusions. This puts those with Parkinson’s and their caregivers in a bind. An adequate dose of L-DOPA might slow the deterioration of motor capacity at the expense of psychiatric wellbeing. In the context of Parkinson’s, hallucinations and delusions can be the price paid for safeguarding the motor capacity to walk, grasp, and swallow.

³ While Parkinsonian hallucinations are most often visual, those with PD may experience hallucinations across all five senses. The evolution from visual hallucinations to hallucinations in other sensory modalities (auditory, tactile, and olfactory) accompanies the progression of Parkinsonian psychosis.

⁴ Parkinsonian hallucinations can be passage hallucinations (where a person or animal crosses the peripheral visual field), illusions (e.g., seeing a dog instead of a plant), and presence hallucinations (a feeling that a person or animal is proximate). Based on her own testimony, my mother experienced all these phenomena at various times.

⁵ The distinction between hallucinations and delusions is salient in the clinical literature on dementia, and Parkinsonian dementia in particular. Hallucinations are “false” sensory perceptions; delusions are false beliefs.

The question my mother posed that day—“are we alone?”—speaks to the liminal phenomenology of Parkinsonian psychosis. The spirits were real to her; of that there was no question. But the fact that she asked if we were alone indicated that, at some level, she was aware that the spirits were spirits. While she would not have used this language, it was clear that in the early stages of her illness, when she engaged with the hallucinations, she often did so with the latent understanding that they did not lay claim to the same ontological status as the cat, me, or my brother. In the current clinical vernacular, this liminal state is referred to as “retaining insight,”⁶ and while he does not call it by that name, it is the perceptual experience on which Maurice Merleau-Ponty (2012) fixates in his discussion of hallucinations in *Phenomenology of Perception*.⁷ There, Merleau-Ponty claims that the hallucinating subject can distinguish between perceptions and hallucinations, a claim he justifies with reference to the “plenitude” that hallucinations lack in reference to “real” perception, insofar as they do not gear into the intersubjective horizon of others’ perceptions in that way that “true” perceptions do (349). “Hallucinations,” he writes, “play out on a different stage than that of the perceived world; it is as if they are superimposed” (355). Merleau-Ponty’s assurance that hallucinations and “true” perceptions phenomenologically differ from one another is grounded in an understanding of perception as spatially and temporally “thick.” By this, he means that variable dimensions are “implied by my own spectacle, just as the back or bottom of objects is perceived at the same time as their visible side, or the room next door pre-exists the perception that I would actually have of it were I to walk over there” (354). Every perception thus implies, by extension, the “insurmountable plenitude” of the phenomenal world. In this account, hallucinations fall short of perceptions to the degree that they fail to gear into the world in the way that perceptions do; Merleau-Ponty’s claim is that they do not anticipate, echo, or communicate with other things in the phenomenal world in the way that a “real” perception does. But it is not only that hallucinations do not anticipate or imply other aspects of the phenomenal world because they are not of a piece with them; hallucinations also fail to accomplish a level of perceptual traction because they are not endorsed by others. In this sense, the “thickness” of perception is (to a meaningful degree) bestowed by others, as they implicitly and explicitly endorse the horizons of my own phenomenal world. The hallucination, lacking the traction and depth of perceptions that are intersubjectively confirmed, “slides across time, just as it slides across the world” (355). Merleau-Ponty’s claim is that varying degrees of intersubjective traction, depth, and thickness manifest as a salient difference between the phenomenality of hallucinations and “real” perceptions.

This phenomenology of hallucination is germane for many at the onset of Parkinsonian psychosis: in the beginning, those who experience hallucinations typically experience them with insight. This means that they are able to recognize the hallucinations as a symptom of their disease, and to understand that they are not real. Indeed, in the early days of my mother’s dementia, it was impossible for me to occupy the exact same space-time as a hallucination. I laid claim to an ontological density that they lacked, so if I moved into

⁶ “Insight” is the recognition that experiences are hallucinations. Insight is typically lost as Parkinson’s disease progresses. Some clinical literature refers to hallucinations with insight as “pseudohallucination.” See Dominic Ffychte et al. (2017).

⁷ See also Sergio Benvenuto (2015).

the same visual plane that they occupied, my presence would dissipate the hallucinations. If I took a seat on the couch where a hallucination was already sitting, for instance, the hallucination would dissolve. For this reason, advice for caregivers for those with Parkinsonian dementia occasionally includes the tip that one can contest hallucinations simply by moving to where they are. As long as insight is retained, the perfect syncing of “real” and hallucinatory realities is not possible. My own ontological density was sufficient to displace the hallucinations if and when our spatial and temporal locations overlapped.

Merleau-Ponty’s sequestering of hallucination apart from “true” perception, no less his rather categorical conviction that those with hallucinations maintain a capacity to differentiate between them, are assumptions readily troubled through the acknowledgement that not all hallucinations are known as hallucinations by those experiencing them. Indeed, hallucinations can grip the subject in ways that foreclose any possibility of recognizing them as such. Nonetheless, Merleau-Ponty’s recognition that the experience of hallucination might be one in which the subject moves (lucidly) between striated ontological levels remains an accurate account, and a helpful one for understanding the paradoxical perceptual architecture of “retaining insight.” Likewise, Merleau-Ponty’s recognition that even hallucinatory perception participates in “that movement that carries us beyond subjectivity, that places us in the world prior to every science and every verification through a sort of ‘faith’ or ‘primordial opinion,’” nods toward the impact of hallucinations, and to why and how they matter, in registers both ontological and ethical (2012, 359).

II. PLAYING ALONG OR BEING WITH?

For some time, I enjoyed a special kind of ontological density (and priority) in my mother’s phenomenal world. As her Parkinson’s progressed, however, and insight was lost, mom began to afford the hallucinations greater and greater credence. It was common for her to start talking with them and interacting with them. At this stage in the evolution of Parkinsonian dementia, the hallucinations may become more protracted, and can cause agitation, fear, and aggressiveness.

Literature on caring for those with advanced Parkinsonian dementia often urges caregivers to refrain from arguing with, or contesting, the hallucinatory landscape.⁸ On the one hand, the rationale for this prescription is ethical, borne of compassion; arguing with or about hallucinations can be deeply distressing for the one experiencing them, and can even be unsafe. Contesting hallucinations can cause panic, anxiety, and harm. Of course, the clinical recommendation is also pragmatic: typically, there just isn’t much point in arguing. Indeed, Parkinsonian hallucinations count as such because they are phenomenologically salient for the one experiencing them and casting them into doubt is not often efficacious. Hence the clinical advice is often to go with the flow and play along.⁹

⁸ See Gail Weatherill (2020). Also see the Parkinson’s Foundation’s (2018b) *Cognition: A Mind Guide to Parkinson’s Disease*.

⁹ See the Parkinson’s Foundation’s (2018a) *Caring and Coping: A Caregivers Guide to Parkinson’s Disease*.

It is the above prescription that I aim to trouble here, on phenomenological grounds. While I agree that, in certain circumstances,¹⁰ it is helpful to engage with, and endorse, the hallucinations, I contend that the language of “playing along” does not adequately or sincerely capture the overlapping worlds of sense that can occur in such contexts. Indeed, such language rings of infantilization, albeit, well-intended.¹¹ The implication is that there is some pretense or inauthenticity involved: what is happening is rendered in terms akin to a child’s game of make-believe. The trope of “playing along” artificially cleaves the phenomenal world in two, reinforcing the idea that the caregiver remains anchored within the bounds of the “real” and “true” perceptual world, while the cared-for is given over to a distorted phenomenological and ontological landscape that is typically understood as little more than a phantasm, a world of deception and illusion. The caregiver may engage this hallucinatory “pseudo-reality” for the sake of offering reassurance and keeping the peace, but in the reigning clinical perspective, is never called upon to question the veracity of their own perceptions. In my experience, however, this view elides the genuine overlap in phenomenal worlds that can occur in the context of caregiving for those with dementia. What this bifurcated ontology fails to capture are the ways in which my mother’s hallucinations, the spirits, became real to me, too, which is to say they mattered to me, even as they remained invisible, inaudible, and unlocatable within my own perceptual horizons.

The hallucinations were significant in ways that surprised me. They kept mom company during the hardest time in her life, and they eased her loneliness as she navigated a profoundly isolating illness. The spirits were with her, they attended to her, and as her Parkinson’s progressed, the spirits became a familiar presence to me, too, one that impacted my sense of my mother’s wellbeing in unexpected ways. Merleau-Ponty’s notion of the perceptual faith—understood as the credence we afford to the phenomenal world as it appears to us, before and beyond questions of judgment, knowledge, justification, or proof—is helpful here. The perceptual faith is the belief that what we see and sense requires no proof or justification. It is a faith that does not occur at the level of knowledge. Merleau-Ponty writes, in *The Visible and the Invisible*, that “the methods of proof and cognition . . . do not enable us to understand what the perceptual faith is, precisely because it is a faith, that is, an adherence that knows itself to be beyond proofs . . . at each instance menaced by non-faith” (1968, 28). Considering its fragility and vulnerability to doubt, Jack Reynolds (2020) rightly notes that the perceptual faith is consistently understood by Merleau-Ponty as both a paradox and a problem for us. The faith I have in the world that I see, touch, smell, hear and taste is braided through with doubt, but it is a commitment nonetheless, one that tethers me to the world, offering me the assurance that what I see and sense is real. In the face of a loved one’s hallucinatory psychosis, there may be a temptation to reify the phenomenal givens of the perceptual faith, to shore up the veridicality of one’s own

¹⁰ This account is concerned with what it means to care for another who is hallucinating, but who does not pose an immanent risk to themselves or others. The clinical recommendation to “play along” is not meant to apply in cases where endorsing another’s hallucinations may cause harm.

¹¹ See Lisa MacFarquhar’s (2018) “The Comforting Fictions of Dementia Care” in *The New Yorker* for a discussion of the well-intended manipulation and deception of those with dementia, and the moral quandaries that attend these practices.

perceptual horizons. In my experience, however, caring for mom required the opposite: a loosening of the grip,¹² an expansion of my own phenomenal world via my acceptance of her hallucinatory landscape.¹³ My experience of my mother's hallucinations taught me that, as often as not, what was called for was not the contraction or consolidation of the perceptual faith, but its relaxation and expansion—not for the purposes of “playing along” so much as being-with.¹⁴

Merleau-Ponty writes: “Insofar as he has sensory fields and a body, the normal subject himself also bears this *gaping wound* through which illusion can be introduced: the normal subject's representation of the world is vulnerable” (2012, 358; emphasis mine). By defining susceptibility to illusion as a potential site of wounding or injury, Merleau-Ponty betrays something significant about who he takes the “normal” subject to be, i.e., one whose perceptions guarantee their reliable anchorage in the “real” world. However, this passage also implies Merleau-Ponty's recognition that perception's purchase on reality is fragile. If even the “normal” subject bears the “gaping wound” that is vulnerability to hallucination or delusion, the gaping wound itself becomes normative. In this account, the possibility of hallucination and delusion consistently haunt perception; perception and the specter of hallucination are thus braided together. And here is the other side of Merleau-Ponty's story: if he is fascinated by the phenomenal difference between perception and illusion, he is also sure that the two are radically interconnected. As he writes, “my confidence in reflection also comes down to taking up the fact of temporality and the fact of the world as the invariable frame of every illusion and every disillusion: I only know myself in my inherence in the world and in time; I only know myself in ambiguity” (360).

Most relevant here is Merleau-Ponty's identification of the perceptual faith as a site of vulnerability, which allows for a reimagining of the perceptual faith as a site of ethical solicitation and response. Here, the perceptual faith is understood as a site of potential injury and abandonment in the event that one's own perceptual horizons cease to sync up with that of others. So, too, the perceptual faith becomes a potential locus of responsibility, care, and fidelity. Its ethical significance cannot be captured in ontological and epistemological registers alone.¹⁵

¹² In “The Phenomenology of Rheumatology: Disability, Merleau-Ponty, and the Fallacy of Maximal Grip,” Gayle Salamon argues for “the insufficiency of grip as an apposite metaphor for wordly engagement” (2012, 244).

¹³ This is not to deny those instances in which the endorsement of hallucinations would cause harm, either to the one having the hallucinations or others. There are many such instances. In this paper, however, I am concerned with the possibilities for coexisting with hallucinations that are for the most part benign.

¹⁴ The relaxation and expansion of the perceptual faith arguably enables us to share in many experiences where the other's phenomenal world does not neatly map on to my own, and my own perceptual “style” may differ radically from another's. This dynamic does not apply in the case of hallucination alone.

¹⁵ In *Disorientation and Moral Life*, Amy Harbin (2016) looks to experiences of disorientation for the role they play in nudging us to cultivate deeper understandings of vulnerability. In “Being at Home: A Feminist Phenomenology of Disorientation in Illness,” Corinne Lajoie (2019) draws on Harbin's work in order to explore the generative aspects of disability in illness: “The instability of bodily dwellings in experiences of disorientation,” Lajoie writes, “can suggest ways of being in the world that are more attentive to interdependency, unpredictability, and change in human experience” (Lajoie 2019, 546).

Emmanuel de Saint Aubert (2021) captures this ethical dimension of the perceptual faith beautifully in his essay on “The Perceptual Foundation of Care” when he writes that “the perceptual attitude, thus understood, proves to be at the foundation of care” (2021, 189; 192). While Saint Aubert does not cite the passage from *Phenomenology of Perception* on the “gaping wound” that is exposure to hallucination and delusion, the idea is deeply resonant with his own elaboration of the relationship between perception and care: “To perceive is already to take care of the perceived being. If at least we understand that perception opens onto the vulnerability of this being by opening, beneath itself, onto something more fundamental. And that ought to be at the foundation of care” (191).

René Descartes, too, was preoccupied with perception’s vulnerability to deceit, but the Cartesian response was to shore up the perceptual faith with reference to what is most clear, distinct, and indubitable. More tellingly, indubitability itself is linked, in Descartes’ (2006) Second Meditation, to what is most proprietary. In the Cartesian frame, what is clearest, most veridical, is so because it is mine. Indeed, Descartes cheerfully concludes his Second Meditation with the reassurance that “I manifestly know that nothing can be perceived more easily and more evidently than my own mind” (19). This is in clear contradistinction to Merleau-Ponty’s account, which understands the veracity of perception to be wedded to other’s confirmation of my own perceptual horizons. It is through and in intersubjectivity that perception acquires its nuance and depth. Anxious and proprietary, the Cartesian account of perception cannot readily speak to what my mother, myself, and the spirits shared. By renouncing the ethical and pedagogical potential of hallucination and illusion, it refuses the possibility of a spirited interworld of ethically-meaningful exploration and care, an interworld of meaningful dialogue between multiple overlapping phenomenal worlds.

Merleau-Ponty nods toward this interworld when he claims that

[w]hen the person suffering from hallucinations says that he sees and hears, we must not *believe* him, since he also says the opposite; rather we must *understand* him. We must not restrict ourselves to the opinions that the healthy consciousness has of the consciousness suffering from hallucinations, and take ourselves to be the sole judges of the proper sense of hallucination. (2012, 352; emphasis mine)

Merleau-Ponty cautions against the hubris at play in reducing the other’s hallucinatory world to a “pseudo-reality.” Contra-Descartes, for Merleau-Ponty, perception is not an act of possession but instead a dispossession and an opening. “What is given,” he writes,

is not myself over here and others over there, nor my present here and my past over there, nor healthy consciousness and its cogito here and the hallucinating consciousness over there . . . rather what is given is the doctor *with* the patient, me *with* another person, and my past *on the horizon* of my present. (Merleau-Ponty 2012, 352; emphasis in original)

The sense that one should engage with, rather than dismiss, another's hallucinations aligns with a position explored in a May 2022 article for *The New York Times Magazine*, which highlights the work of the Hearing Voices Network, a group that eschews the language of psychosis in favor of the idea of nonconsensus realities, and works toward diminishing the senses of secrecy, deviancy, and horror that so often accompany hallucination in the public eye: "Instead, partly by lifting the pressure of secrecy and diminishing the feeling of deviance, the talk will loosen the hold of hallucinations, and, crucially, the grip of isolation" (Bergner 2022).¹⁶ The goal is to work for greater acceptance of patients' experience of voices and hallucinations and to create spaces where people can describe and discuss their hallucinations, thereby refusing the stigma and isolation that too often surround hallucinatory illness. This is not to claim that nonconsensus realities are always benign; no doubt many are profoundly malignant and injurious. Nonconsensus realities can be scenes of horror and abandonment. Moreover, we live in a time when essentially hallucinatory, collectively-held epistemic structures can have devastating and malignant consequences. Hence the injunction to attend to nonconsensus realities is not intended as a universalizable prescription or a recipe for care in all circumstances.¹⁷ The volatility of nonconsensus realities, and the broad spectrum of possible responses to them, must be acknowledged even in the context of projects whose specific aim is to cultivate a greater understanding of hallucination and delusion, and the possibility of responding to them without fear, aversion, or violence.

Experiencing my mother's dementia taught me that the anodyne examples that phenomenologists tend to nominate as illustrations of intentionality don't come close to celebrating the full array of intentional possibilities. The canonical texts often find us reaching for pens and glasses of water. Our movement toward objects is frequently rendered in instrumental and somewhat sanitized terms, in scenes that are often solitary. ("I am sitting at a desk . . . I reach for the glass of water . . ."). But in caring for those with dementia, the intentional arc is reconfigured and vivified. I cannot see, hear, or touch the hallucinations, but I am intended toward them nonetheless. Indeed, the horizons that are opened by caregiving exhibit an expansiveness and ambiguity that classical examples of intentionality may lack. Caring thus illuminates the world in ways that subvert and depart from more orthodox renderings of perception in the phenomenological tradition. Care may guide the radical transfiguration of relationships in illness, in one instance of what Gail Weiss (2008) has called a refiguring of the ordinary. What comes into relief is a spirited interworld whose phenomenological ground is not the reassurance or confirmation of perceptual overlap, but instead the invitation and the desire to see with another, even and perhaps especially when this "seeing" will reveal nothing that is visible to me at all.

¹⁶ The article especially highlights the efforts of Caroline Mazel-Carlton, the leader of the Hearing Voices Network. In an intersectional vein, Mazel-Carlton affirms her wish for the expansion of different options for healing, viewing her efforts as meaningfully aligned with the successful challenge to society's understanding of autism posed by those in the neurodiversity movement (Bergner 2022).

¹⁷ Much of the contemporary literature on hallucination concerns schizophrenia and contexts wherein hallucinations are far from benign and may cause trauma or injury. See Matthew Ratcliffe's (2017) *Real Hallucinations*.

This mode of intention—caring—is the residuum of a phenomenological reduction whose impetus and evidence is interrelation. Bracketing questions of veridicality and truth, what comes into relief through the caring reduction or *epoché* is human relation in its cognitive and ethical complexity. When performed in the register of caregiving, what the reduction reveals is not only the epistemic and ontological fact of our being for and with others, but also the manifest truth that the other’s world matters to me. *Vis-à-vis* hallucination, the question “is it real?” can, and often does, claim less experiential priority than the question “how shall I respond given that this is real to her?”

III. CARING ACROSS MULTIPLE WORLDS

I stood in line at CVS waiting to purchase an over-the-counter medication that my mother had requested. She was convinced that the spirits had tampered with the nearly-full bottle of that same medication she had at home, and was refusing to take the medication for fear it would harm her. Frustrated, she had asked me to go out to get a new bottle. I was at CVS to purchase a medication that I knew we did not need. Standing in line at the pharmacy that morning, I wondered what I was doing. I pondered the privilege of being in a position to buy medicine that we already had in abundance. To do so was arguably absurd, ridiculous, and wasteful. To be sure, I can narrate the decision to acquire the surplus medicine in reference to a desire to keep the peace, to placate my ill mother, to not have the last few weeks with a beloved parent marred by memories of having deceived her. These are all explanations that could have been given for what I was doing, but none of them were exactly on target.

In fact, there was a genuine felt sense that to trick mom into taking the medicines that she believed to be contaminated—(which would have been easy enough to do)—was wrong, not because it would mean I had lied to her or somehow deceived her, but because the medication that felt contaminated for her truly felt contaminated to me, too. It is here where the prescription to “play along”—and the bifurcated ontology (one real, one hallucinatory) that informs it—comes up short. What I was doing in line at CVS that morning wasn’t playing along, or if it was, I was pretty deep in the play myself. The standard view would hold that the medicine sitting on the counter in mom’s apartment was safe in my reality, compromised in hers. But there is a phenomenological register in which this bifurcation blurred, and where these two senses ceased to be mutually exclusive. This is the register of care, whose compass is set to the poles of love and fidelity far more so than any conscious concern with veridicality, skepticism, and truth.¹⁸ Here Emmanuel Levinas comes to mind, both for his recognition of the felt sense of the ethical force of the other’s alterity, and for the priority he assigns this ethical sense above and beyond the registers of comprehension and knowledge.

¹⁸ In “Playfulness, ‘World’-Traveling, and Loving Perception,” María Lugones powerfully describes travel between incommensurate phenomenal worlds and notes possible connections between world-travel and love (1987, 3). The sense of love and playfulness that Lugones explores is certainly relevant here. Lugones also describes world-traveling as *willful*, however, whereas part of what I aim to capture in this account is an involuntary, nonvolitional orientation toward others that is care.

At the beginning of the section on “Sensibility and Proximity” in *Otherwise than Being*, Emmanuel Levinas writes of “making oneself a sign” as an expression of “self, sincerity, passivity” (1998, 62).¹⁹ This passage is nested in a broader discussion of the dynamic between the saying and the said, or between the expressive opening to, and welcoming of, the other, and the particular signs that will render this gesture intelligible within particular social and cultural horizons. What might it mean to “make oneself a sign” in the case of caregiving? In the context of dementia, it may mean looking down at the plate to remind someone that they are eating, or it may mean holding eye contact long enough to dissipate a felt sense of solitude. To “make oneself a sign” in this context is to abide in a phenomenal field that you did not craft, whose contours may be alien and even frightening in their imperceptibility, and to refuse to let the sense of strangeness and alterity that abides there give way to only mystification or fear.

IV. IDENTITY AND ANONYMITY

My mother bakes in the kitchen as I sit some distance from her and watch. I read her bodily comportment, the arch of her back and neck, and I can tell that she thinks there is someone standing behind her. She looks at me across the room and asks: “Am I in your way?” In that moment, it is clear to me that, even though our eyes are locking across a distance of twenty or so feet, she also thinks I am standing immediately behind her, supervising her cooking.²⁰ This was the first of many episodes when I had to reckon with the fact that mom’s hallucinations included multiple versions of me moving through the world simultaneously. Once, when we were out on a walk together, she turned to me and asked: “I wonder if Ann would have liked to come?” Another time, she failed to greet me at the door with the happiness to which I’d grown accustomed. This stung a bit until I realized that mom’s lack of affect was due to the fact that a hallucination of me had actually been keeping her company all morning. Over time, I made an uneasy peace with the idea that I was often co-present with hallucinations of me. Sometimes there was more than one of me in the same room or house; other times I would be right next to mom and she would also think I was several states away. I often suspected that my hallucinatory doubles were acting on my behalf when I was away from her, doing or saying things that I would never know. In the event that my mother had a surprising or sharp emotional response to something I did or said, I wondered if this was because a hallucination of me had already been on the scene, behaving differently, speaking on my behalf, making promises I wasn’t keeping. I worried that it might be confusing for mom to have simultaneous perceptions of the same loved one moving through her phenomenal world.

¹⁹ My thanks to Tim Stock for a series of conversations on *Otherwise than Being* in spring 2022 that brought this passage to my attention.

²⁰ This is known in the clinical literature as a “presence hallucination”: it is the feeling that something or someone is nearby.

While my mother never forgot my name and recognized me as her daughter till the end of her life, it was also the case that in her perceptual reality I had become immune to the laws that typically bind us in our movement through space and time. Hers was a phenomenal world in which I had become a time-traveler; in her world, I routinely kept the company of relatives and kin who had died before my birth. I ate dinner with her in Baltimore at the same time that I taught class in Albuquerque. By now, the ontological density to which I had once laid claim in my mother's phenomenal world had dissipated, and with it her ability to recognize me as singular among the hallucinations, which now included so many other versions of myself. This marked a progression in mom's dementia and a notable change in the hallucinatory landscape. The insight that had been retained was now lost, and mom moved through a spirited world that I was less and less able to track, or participate in, with any regularity, predictability, or efficacy. I slipped into an ontological register that felt strange and depersonalized. In my case, this took the form of being dissipated in a loved one's hallucinations, such that there were multiple versions of me gliding through my mom's phenomenal world in ways I could only roughly track.

I am still thinking through the questions of responsibility that arose by virtue of the fact that, in my mother's experience, there were multiple versions of me caring for her. In the end, I could only be obliquely aware of what this felt like for her, and I could only imperfectly trace the contours of where and when I was for her. There are also myriad questions that emerge regarding what responsibility one has for caregiving when one is already there in some meaningful sense (albeit as a hallucination). These are questions I am still trying to parse. For now, I remain interested in how one can be with dementia in ways that resist the tendency to exoticize or pathologize it. I remain hopeful that we can collectively cultivate the means for being-with dementia, and caring for those with dementia, in ways that transcend the grip of fear, crisis, and aversion.

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