

Infrastructures of Aging: Form and Institutional Care in Dementia Fiction

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Abstract The fictional representation of the cognitive experience of people with dementia is often credited with providing an occasion for readerly empathy and a privileged mimetic account of dementia experience. This essay draws on recent scholarship by Caroline Levine and Anna Kornbluh that expands the notion of form to include infrastructures, institutions, and other entities that provide sustenance and continuity to offer a different account of the cultural work such fictions do. The essay argues that two canonical works of fiction about dementia—J. Bernlef’s *Out of Mind* and B. S. Johnson’s *House Mother Normal*—do not merely offer a mimesis of dementia experience (the focus of existing research). These works take seriously dementia experience’s challenge to formal coherence as they (however ambivalently) displace the task of providing continuity and sustenance to caring institutions rather than to residual ratiocinative capacities. Both novels repurpose the ellipses and blanks that are typical of the representation of dementia “mind styles” for something other than an indication of deficient subjectivity: in Bernlef, they become an indicator of lyrical and timeless sustenance and suspension; in Johnson, they point to regularities that invite the reader to coconstruct an imaginative space that sustains the lives the novel evokes.

Keywords representation of consciousness, dementia, form, institution

1. Dementia, Institution, Form

Dementia and senility used to be considered self-evident aspects of old age; they were the diminished and quiet last part of the narrative arcs through which the organic development of human life was imagined. In recent decades, dementia—and especially Alzheimer’s, the most prevalent if hardly the only shape of the syndrome—has increasingly been isolated from such narrative embedding and has become visible as both a medical challenge and a societal ill. As “the medicalization of dementia has disentangled it from ‘normal’ aging” (Falcus and Sako 2019: 9), dementia has increasingly been recast less as an undeniably reduced and challenging form of human life than as a radical loss of what defines human life (Zimmermann 2020: 5): a loss of memory, of mobility, of autonomy, of linguistic power, of dignity. Instead of an eccentric position on a spectrum of forms of human being, dementia is positioned beyond that spectrum as a “black hole” and a condition of “inherent unknowability” (Falcus and Sako 2019: 10)—as, in the terms that this special issue invites, a challenge to form. The images through which aging Western societies imagine the societal aspects of the increasing prevalence of dementia similarly construe it as a phenomenon that overwhelms the mind’s capacity to impose form: this increase is figured as an “emergent silent tsunami” or a “rising tide” about to drown welfare systems, while people with dementia are presented as mindless zombies or (in the visual rhetoric of innumerable stock images) puzzled faces oblivious to the fact that the backs of their heads are quietly but inexorably blowing apart (Werner et al. 2022: 28). These images show Caroline Levine’s (2015: 3) expansive understanding of form as any “*arrangement of elements—an ordering, patterning, or shaping*” to be somewhat too broad: even if tsunamis, floods, and explosions are indeed marked by a certain patterning and order, the fact that the human mind cannot readily recognize those patterns because of their excessive complexity, speed, or proximity makes it more useful to consider these phenomena as a *challenge* to form. When discussing the textual operation of literary texts (as this essay does), it is more accurate to limit our understanding of form to apparent patterns and orders that readers’ minds and bodies can discern, and to see elements that challenge that capacity as something other than form (even if, ontologically, they are marked by order and regularity).

Since the 1990s, biomedical approaches to dementia have been criticized for exacerbating the devaluation and dehumanization of the lives they purport to describe and improve. Dementia scientist Tom Kitwood has been influential in showing how the process of dementia is a consequence not only of neurological degeneration but also of the socio-psychological

attitudes that compound processes of “disempowerment, infantilisation, labelling, and objectification in the progression of dementia” (Bitenc 2020: 11). Kitwood (1997) diagnosed a “malignant social psychology” that (often unwittingly) disparages and stigmatizes people with dementia, and he proposed a “person-centered” approach as an alternative. Personhood, for Kitwood (8), means “a standing or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect, and trust.” The person-centered approach insists that in interpersonal relations people with dementia interact as proper agents whose preferences, well-being, and reactions matter. Far from considering dementia as an inherently unknowable black hole, the person-centered approach insists that dementia be “perceived as an understandable and human condition,” and that “those who are affected by it . . . be recognized, welcomed, embraced and heard” (133).

Effecting such a change requires nothing less than “a cultural transformation” (133), and it is here that literature has in the last several decades come to play an increasingly vital role. Peter Simonsen (2017a) has referred to the spectacular rise of dementia literature as a “literary epidemic,” a term that captures the proliferation of different genres of engagement with dementia: autobiographical writing (typically produced by people in the early stages of the disease), caregiver accounts and memoirs, fictions narrated from the perspective of people with dementia, and also graphic narratives, whose visual affordances are often taken to compensate for the unspeakability besetting dementia (Bitenc 2020; Zimmermann 2017). For all the obvious differences among these genres, especially in terms of the perspectives from which they represent dementia (first- or third-person, caregiver or patient, documentation or retrospection), the scholarship on this burgeoning archive customarily underlines the “oxymoron” or “paradox” of “narrativizing experience that is considered to resist language and chronological order” (Zimmermann 2017: 7; Falcus and Sako 2019: 12). This paradox has been less a constraint than a catalyst for literary production (think of successful works such as John Bayley’s *Iris: A Memoir of Iris Murdoch* or Lisa Genova’s novel *Still Alice*). Across the different versions of dementia literature, narrative imposes an order and pattern on a challenging reality that seems to resist it, and it is this affirmation of narrative continuity—for Shlomith Rimmon-Kenan (2002) the defining feature of illness narrative—that assists the “cultural transformation” that allows people with dementia to be recognized as full-fledged agents and persons. In narrative engagements with dementia, then, the affirmation of a recognizable, manageable form and the recognition of personhood go hand-in-hand.

But doesn't this effort to impose continuity and coherence on a condition that is marked by disorientation and confusion risk misrecognizing the condition it aims to capture? Martina Zimmermann (2020: 137) has described how narrative coherence has increasingly given way to fragmentation in the representation of dementia, while Irmela Krüger-Fürhoff (2015: 92) has noted how the emphasis on narrative perpetuates a notion of identity and selfhood that relies on memory and storytelling capacities, the very things that dementia slowly erodes. The literary attempt to affirm personhood, in other words, like the biomedical approaches it seeks to amend, risks misrecognizing the lives it putatively wants to elevate. While this problem with the continuities of narrative in dementia fiction leads Krüger-Fürhoff to focus on literature's self-reflexive capacity to narrate the limits of narration, Rebecca Bitenc (2020: 7) argues that narrative simply fails to capture "embodied and relational aspects of identity in dementia." Dementia literature is marked by what W. J. T. Mitchell (2003) called a "commitment to form"; what it seems to be unable to conceive is the particularity of a kind of life that is *not* marked by narrative continuity, by reflection and self-awareness. What is missing, I mean to argue, is a kind of literature that does not misrecognize dementia's radical challenge to form and that *situates the search for pattern and regularity elsewhere than in the mind*.

I argue in this essay that a particular strand of dementia fiction can best be characterized as an attempt to convey form without misrecognizing the experience of dementia: the kind of fiction that represents the "mind style" of a person with dementia, either homodiegetically or heterodiegetically with access to the character's cognition (Lugea 2022: 173). I read two classic fictional accounts of dementia—J. Bernlef's 1984 novel *Out of Mind* and B. S. Johnson's 1971 "geriatric comedy" *House Mother Normal*—as attempts to find a form for dementia that does not rely on narrative continuity or on the related strategy of representing complex ratiocination and self-reflexivity. While earlier criticism of these novels has emphasized their ambition to offer a mimetic representation of dementia consciousness and at times (correctly) faulted them for indulging a negative vision of dementia as a hopeless and abject condition, I turn to recent expanded theories of literary form to reread these novels as centrally concerned with the importance of patterns and regularities. In both these works, the task of providing continuity and sustenance shifts to what these theories have invited us to imagine as *also* kinds of form: infrastructures, welfare provisions, and other institutional supports that sustain vulnerable lives. There are, of course, sound political and strategic reasons to question the consideration of institutions as forms—for one thing, this approach may blunt analyses of power. Still, I argue that, when discussing the role literature can play in

measuring up to the complexity of dementia, it is important to recognize that *allegorizing institutions as form* is one of literature's key affordances for engaging the extraliterary world. I propose a reading of dementia fiction in which the project of finding form is not a matter of adequately representing the cognitive experience of a person with dementia, but is instead radically bifurcated between two elements: an attempt to give literary form to a life bereft of customary capacities for reflection and self-perpetuation on the one hand, and an attempt to convey that these capacities need to be assumed by sustaining and nurturing institutions on the other. Rather than reading the growing trend to use fragmentation in dementia narratives as a *mimetic* project to capture the reality of dementia consciousness (a project that, as I show, ends up reinstating the normative accounts of subjectivity it aims to move beyond), I propose a consideration of the strand of dementia fiction that I am interested in here as a non-mimetic but future-oriented and *constructive* project that emphasizes the affordances of institutions, patterns, and other forms for sustaining life.

2. Constructing Form, Representing Consciousness

In arguing for dementia fiction's commitment to an extended notion of form, I want to enlist the subgenre for the more affirmative impetus that underwrites recent calls for attention to form in humanistic research. These calls draw analogies between literary and artistic mediations of form, on the one hand, and the regularities of institutions, on the other—an analogy that can be questioned in terms of political strategy and social analysis, but that I find invaluable in thinking about the power of literature to engage complex social issues. Anna Kornbluh (2019: 2) figures her own commitment to formalism against a dominant strand of what she calls “anarcho-vitalism” in critical theory—a tendency to focus on the extreme, the singular, the destitute, and whatever resists order and articulation. Kornbluh nominates Giorgio Agamben's figure of “bare life” (developed in the context of his reflections on the Holocaust) as a prime example of this tendency, and it is no coincidence that this figure of a life reduced to its nonhuman residue has become an important reference point in the imagining of dementia (Cohen 2006: 11; see Burke 2019). Equating dementia and bare life amounts to an embrace of utter formlessness, one which critical dementia research and literature have over the last decades shown to be problematic. Tying the imagining of dementia to formlessness either surrenders it to cultural anxieties over an uncontrollable phenomenon that erase the particularity of the condition or, alternatively, invites inflating the mental state that marks dementia into a form of visionary and prophetic

insight (where dementia's difference from normative forms of rationality is recast as a form of wisdom), as literature and critical theory have repeatedly done (Burke 2019; Vermeulen 2022). For Kornbluh (2019: 161–62), an emphasis on singularity and demolition is a strategic mistake: it prevents the humanities from engaging with “infrastructure and organization and formation” and with ways of making the humanities' ethical and political commitments permanent and sustainable. Kornbluh, like Caroline Levine (2015: 56), finds power of “endurance” in form—and this is a feature of form that is crucial for my reading of dementia fiction. This emphasis on “sustainability, or collective continuance” (Levine 2021: 231) takes center stage in Levine's most recent work, which calls on the humanities to embrace an “affirmative instrumentality” that abandons an engrained obsession with anti-instrumentality and the autonomy of art and instead attunes readers to “infrastructure for living”—forms like “healthcare and social security”—that foregrounds the mundane work of maintenance, of “sustaining living bodies over time” (232–35).

In the context of dementia care, it is not hard to see that an affirmation of sustenance is predicated first and foremost upon a fiscal commitment to care facilities. Dementia is perceived as a threat to Western audiences not only because the cognitive decline that defines the condition carries with it a loss of the autonomy, mobility, and independence that we understand to be constitutive of human subjectivity, but also because the proliferation of dementia puts immense pressure on social welfare infrastructures that have already been eroded by neoliberal policies (Vermeulen 2022). Meeting the societal challenges of dementia, then, requires fiscal commitments to care provisions—to, in Levine's and Kornbluh's terms, forms and infrastructures that can sustain and maintain forms of life that undeniably rely on such constructive commitments. Rather than abstracting the reality of dementia into radical hopelessness, as Agamben-inspired discourses do, tying dementia to form helpfully shifts the debate to the less apocalyptic scale of “the ethics and politics of long life, illness, dependency, and care” (Burke 2019: 18). Representations of the care home in dementia literature have up until now been largely ambivalent, even if there are instances of positive representations in Canadian and Scandinavian fiction (Berndt and Henke 2017; Simonsen 2017b). Finding a form for life's dependence on caring infrastructures, I argue, is thus a key and understudied aspect of dementia literature's negotiation of form. My readings of *Out of Mind* and *House Mother Normal* show that dementia fiction's negotiations with institutionalization are deeply, if ambivalently, connected to those fictions' attempt to find a form for the experience of dementia. More specifically, these novels situate the attempt to find form not in the place where

we customary look for it—in consciousness representation (Kruger 2015: 118)—but in very different narrative features: larger-scale regularities such as a consistent layout (in *House Mother Normal*), an almost imperceptible erosion of homodiegetic narration (in *Out of Mind*), and links between these narrative operations and an engagement with institutions on the levels of plot and theme (in both works).

Ever since 1984, when Bernlef's *Out of Mind* offered “the first book-length fictional account consistently told from the patient's point of view” (Zimmermann 2017: 5), literary fiction has mobilized its capacity to narrate consciousness to evoke the experience of living with dementia. It has drawn on the modernist tradition of the stream of consciousness to capture the nonlinearity and confusion that we generally assume dementia consciousness to consist of. While the term *stream of consciousness* is often very loosely defined (even if it reverts to an extremely small and rigorously codified canon of authors; Palmer 2004: 23–24), there is a shared expectation that it “must be first person, associational, and unmediated,” and marked by an “overemphasis on rhyme and phrasal repetitions” (Bowler and Drewery 2020: 7). Still, in spite of the device's emphasis on “the random, associative, illogical, and seemingly ungrammatical” (Palmer 2005: 570), narratologists have shown how rhetorically and narratologically complex typical streams of consciousness are (Bernaerts 2014; Palmer 2004), and how many passages contain a “dense mixture” of different direct and indirect modes of thought representation and surface descriptions of the physical storyworld (Palmer 2005: 571). As I noted, it is this complexity, which evokes reflexivity and metaperspectives (such as a capacity for spatial and temporal orientation or for intentional remembering), that is simply not available to the consciousness of subjects in the advanced stages of dementia.

Finding a form for dementia, then, means looking elsewhere than in complex consciousness representations. Stephan Millett (2011: 510) observes that “there is a life-world . . . for people with dementia, who continue to experience the world and create meaning, even in the presence of severe cognitive degradation.” Thomas Fuchs (2020: 665) echoes a scientific consensus when he notes that, even if people with advanced dementia are deprived of biographical memory, they continue to experience “a self-givenness of the continuous stream of consciousness as such.” As Fuchs writes, “such a basal self-experience remains intact even in late stage of dementia.” Advanced dementia, that is, is marked by a form of minimal self-experience that is deprived of “the higher-order capacity of *reflexivity and decentering*”—of the “particular human capacity of stepping out of one's bodily center and taking a virtual perspective on oneself” (66g). Dementia is marked by an inability to distance oneself from immediate experience—

from the place, time, and subject living the experience—so that only a mere stream of consciousness *without* reflexivity remains.

My reading of *Out of Mind* and *House Mother Normal* shows that self-reflexivity and metaperspective are not the only literary strategies for providing continuity: these novels allocate the role of providing continuity and support in the story world to mind-external institutions and infrastructures that they both name and, as I show, evoke through formal means. In analyses of two key dementia novels, this essay argues that the unpredictable, shifty, and unstable nature of dementia narrative can productively be read as a struggle to find a form that is *not* reliant on reflexivity and on shifts toward a metaperspective. This struggle is reflected in these works' ambivalence about institutional care—the kind of form and infrastructure on which life (with or without dementia) relies for “maintenance and continuity” (Levine 2021: 242). In this way, dementia fiction can, in Levine's terms, be read and instrumentalized as a genre that makes readers appreciate the importance of infrastructures and institutions for providing the sustenance all vulnerable lives depend on.

3. Closing the Gap: J. Bernlef's *Out of Mind*

J. Bernlef's 1984 novel has established itself as a classic of dementia literature. The novel represents the disintegration of the mind of Maarten Klein, an aging Dutchman who migrated to the United States to work for the International Maritime Consultative Organization and slowly loses his grip on life. His thoughts increasingly mix up the reality of his quiet life in Massachusetts with memories of youthful love, the Second World War, and the troubles of migration (a mixing of discourses that has been analyzed as typical of the “mind style” of dementia narrators; Lugea 2022: 182–84). As is fairly typical of first-person dementia fiction, an increasingly elliptical style as well as lexical and grammatical reduction and pronoun shifts toward the end of the novel (“Walking dozily . . . shuffling . . . his shoes are gone . . .”; Bernlef 1988: 126) are employed to evoke Maarten's neurological degeneration. Throughout the novel, the perspective never wavers from that of Maarten: as Rebecca Bitenc (2020: 74) remarks, he “remains the centre of consciousness and perception.” By not distancing itself from that consciousness the novel underlines “his continuing identity, suggesting that lower-order cognitive functions might be sufficient to accord personhood or at least selfhood to a subject” (Bitenc 2020: 74), even if near the end, the novel begins to shift between first, second, and third-person narration without ever fully abandoning the first person.

Is Bernlef's novel, then, as Alexander Zweers (1998: 35) has argued, “an

attempt to experiment with how much can be taken away from a human mind and still leave a narrator who can tell a tale comprehensible and attractive to the reader”? I believe it is, but this ambition for comprehensibility also means that most of the novel misrecognizes dementia’s radical challenge to formal cohesion—as Zweers acknowledges when he remarks on the discrepancy between the narrator’s mental state and his “still remarkable writing and composition skills” (38). This discrepancy means that *Out of Mind* is not a *mimetic* project that attempts to convey the reality of a mind with dementia. The disintegration of thought occurs relatively late in the novel (Bernlef 1988: 98, 111), but before that, the narrator’s grammatical and semantic capacities as well as his capacity to accurately render conversations are almost fully intact. Maarten experiences moments of forgetting, but paradoxically manages to keep track of these moments: he articulates that “[he] keep[s] missing links . . . a fair amount can be reconstructed . . . sometimes there are such large gaps . . .” (87). For most of the novel, Maarten can adequately *name* “this feeling of being absent while being fully conscious,” (9) the inability to “form a precise picture of what that means: the situation” (15). He still has a higher-order awareness of other minds, as when he observes that his dog “lives in the same world as I, and yet he must experience it quite differently” (33). Such a capacity to adopt a metaperspective on the here and now is precisely something that is missing in the real experience of dementia, which is marked by a disturbance of spatial and temporal orientation and a decline in intentional remembering (2020: 669–70).

This capacity to abstract from the present persists in a key passage near the end of the novel:

Question of mistake or exchange? . . . a tall bare space with concrete flower troughs full of pitch-black earth . . . no flowers only scuffed kitchen chairs . . . men and women in mouse-grey overalls . . . sometimes distant, sometimes frighteningly near.

SUDDENLY THEY ARE STANDING BEFORE ME

deportation? . . . only English is spoken here . . . through large windows: a view of a tall brick wall . . . (Bernlef 1988: 119)

Critics have praised the novel, and especially late sections like this one, for “offer[ing] an alternative to conventional notions of coherence and narrative identity,” as words are omitted, phrases italicized or capitalized, personal pronouns used erratically, and fewer and fewer aspects of the diegetic context enter into the stream of consciousness (Krüger-Fürhoff 2015: 104). It is these latter aspects that explain why it is harder for the reader here to infer what is actually going on: Maarten is taken to a care facility, which he

perceives as the process of being deported to a concentration camp (readers are likely to infer such connections because of the references to migration and the Second World War earlier in the novel). The novel mobilizes different devices to convey Maarten's diminishing grasp on his surroundings: the typographical variation indicates a lack of equanimity; the ellipses mark discontinuities in his registration of the world, as well as a lack of connection between different parts of his perception (as in the sudden shift from chairs to people).

Still, I would argue that Bernlef's novel is, for all that, *not* a successful *mimesis* of dementia experience. Even in the passage above, the tension between immediate perception and a metaperspective is still evident when we notice Maarten's residual capacity to register negativity (Bernlef 1988: 9): he notices there are "no flowers" and there is "only English . . . here," which points to his awareness of the possible (that is, counterfactual) presence of flowers or other languages. This capacity for envisioning alternative realities means that his perspective is not fatally riveted to the present; it displays what Fuchs (2020: 669) refers to as the higher-order capacity to deploy the "symbolic or 'as-if' function," to appreciate "the distinction between reality and virtuality." Selfhood, in *Out of Mind*, is still predicated upon the ability to transcend the present, rather than upon the inevitability of inhabiting it.

The same might be said of Bernlef's decision to convey Maarten's diminishment through ellipses and gaps. This approach means that the novel imagines his condition less as what Fuchs (2020: 665) refers as the "basal self-experience" of a "continuous stream of consciousness," *which is characterized by the absence of gaps*, than as a perforated neurotypical consciousness—which is to say, as a diminished version of the fully functional consciousness that largely persists in the novel's first hundred or so pages. In other words, the novel's reliance on gaps for conveying its version of life with dementia (and also, as Rebecca Bitenc (2020: 73) has remarked, on parentheses that register a continuing "dual awareness") betrays that it conceives of such a life as an encroaching loss of form, rather than as a new mode of organization, a new kind of selfhood. In his blurb for the novel, Harold Pinter describes how "Maarten's mind leaks away . . . and finally dissolves," while Ian Sinclair calls it "a mental odyssey into disintegration and nothingness"—formulations that correctly foreground this turn to formlessness. Critics like Bitenc and Krüger-Fürhoff, I want to suggest, correctly read the novel's demolition of form as an innovation in dementia narrative; at the same time, even this innovation, I believe, does not imagine dementia experience as a full-fledged form.

I argue that the novel's most important contribution is its interrogation

of the role of regularity, patterns, and predictability for sustaining vulnerable lives. As Caroline Levine (2021: 242) notes, providing “maintenance and continuity” is precisely the work of institutions and forms. It is unsurprising, then, that the novel’s struggle to find a form for registering the expression of both dementia and structures of sustenance is reflected in an ambivalent relation to institutions. The novel’s opening two pages abound with references to institutions that provide predictability and routine. At the very beginning of the novel, Maarten reflects on the snow outside: it is a condition “when the traces of man vanish from nature, when everything becomes one immaculate white plain” (Bernlef 1988: 1). The narrator here believes that “this state of affairs never lasts long,” as footprints and tire tracks soon provide orientation (1). The tires that provide orientation in the snow are those of the school bus that reliably stops before Maarten’s house “every morning”; the foghorn and the lighthouse are other markers of regularity—“You can set the clock by them”; and there is the memory of Maarten’s father, who worked as “a clerk to the court practically all his life” and who was committed to “recording facts,” dutifully noting temperatures every morning and evening—“he used to like systems” (1–2). From the beginning, then, the novel foregrounds the extent to which institutions and public provisions (courtrooms, schools, lighthouses) are infrastructures for providing the routine and maintenance that, as Levine (2021: 232–33) notes, makes it possible to “sustain collective life over time with some degree of justice and mutual care” by doing “the work that keeps life going every day.”

As the reader follows Maarten’s increasing vulnerability and dependence throughout the novel, this reliance on external support becomes increasingly palpable. Maarten’s development over the course of the novel is a process in which the outside world ceases to provide orientation, order, pattern—that is, ceases to provide form. The novel is characterized by acute and intense descriptions of the object and animal worlds, which, often at the beginning of passages, provide the narrator with a sense of stability and orientation, as if to anchor his sense of observation in the real world. (This stabilizing power is especially apparent in scene-opening descriptive sentences such as “I am standing by the window in the back room and looking at two scrawny squirrels chasing each other up the trunk of a crooked birch tree” [41] or “I stand in the back room and watch [the dog] nervously circling round an ash tree and jumping up against it . . .” [62].) Gradually, these descriptions make way for scenes such as the one where, as Krüger-Fürhoff (2015: 103) notes, the novel deploys a familiar trope in writing about aging—that of characters failing to recognize themselves in the mirror: “I pick up the toothbrush and look in the mirror. There isn’t

anyone there. Everything is white” (Bernlef 1988: 98). When not even the mirror provides recognition, the novel signals that the outside world no longer provides continuity, stability, and predictability (while it also shows that this is less a claim about the world than about the perspective from which it is registered). Dementia, in *Out of Mind*, is also a crisis of support and sustainment.

For Levine, a commitment to maintenance and institutional care entails a particular aesthetics: instead of a poetics dedicated to the high modernist values of “ruptures and unpredictability,” to works that “disrupt expectations and conventions,” she argues for forms that affirm the “powerful pleasures” of routine, repetition, and regularity (2021: 240–44). What we need, Levine suggests, are “aesthetic and cultural forms that can help us to appreciate the affirmative affordances of routines” (242). Yet as *Out of Mind* makes clear, this aesthetic program will not quite do for dementia fiction, as the form of life it depicts is precisely characterized by the impossibility of reliable regularity and routines; indeed, one thing that makes people with dementia radically dependent on the routines of maintenance is their inability to independently manage their lives. Dementia fiction, then, needs to balance the contradictory imperatives of advocating the “affirmative affordances” of routine on the one hand and of giving shape to an experience bereft of such order and confined to the now of experience on the other. This is an experience where rupture and unpredictability are unavoidable.

The difficulty of representing narrative unpredictability and sustenance is only resolved at the very end of the novel. When Maarten is institutionalized near the end of the novel, his experience is initially one of terror and disorientation, in which his earlier memories of the war and of migration lead him to experience the threat of incarceration or deportation. It is only on the last page that we see an intimation of institutional and formal continuity. In the final two paragraphs, the novel connects institutionalization to the daily work of sustaining vulnerable lives—and remarkably, it does so at a moment when it also imagines life with dementia, I would argue, *beyond* the framework of narrative identity (a framework, that is, in which that life can only be found wanting). The penultimate paragraph sees the narrator find support in a passage that combines personal and impersonal care settings: “. . . her hand will come to you . . . here . . . first take that hand that gropes aimlessly in the dark . . . take it gently . . . calm him . . . now you no longer need to hold anything yourself . . . she will do that from now on . . .” (Bernlef 1988: 129). The representation of consciousness is marked by shifting personal pronouns, alternating tenses, and unstable referents (the female figure here may refer to Maarten’s wife,

mother, or a former lover; more disturbingly, she may also be a personification of death), which makes this a scene of more than just interpersonal care; the overall result is a sense of sustenance that extends into the future and promises continuity. This work of perdurance survives the night, and it continues into the morning: “. . . into the woods and the spring that is almost beginning . . . she says . . . she whispers . . . the spring which is about to begin . . .” (130). Here, life with dementia moves beyond the frustrating mandate to find tracks and orientation in the snow and is imagined as a new season rather than as a defective form of an older one. It is in these final paragraphs, which are explicitly set in a nursing home, that *Out of Mind* may most successfully contribute to what Peter Simonsen (2017b: 185) has called “the cultural work of reimagining the nursing home as a place of continued living and even loving and happy forgetting.” Significantly, it does so at the moment it manages to imagine dementia as more than a defective and diminished form of life.

But what about the ellipses that continue to mark these final paragraphs, and that we earlier took to indicate a fateful gap between the now of experience and the capacity to transcend immediacy and access a metaperspective? I argue that the ellipses in the final two paragraphs function differently from those in the preceding pages. Alan Palmer (2005: 570–71) has remarked that the notion of stream of consciousness brings together two contradictory meanings: some accounts situate it in the story or *fabula*, as a feature of the presented world, while others consider the typical features of stream of consciousness as part of the techniques deployed in the discourse, or *syuzhet*. The gaps earlier in the novel operated on the level of the *syuzhet*, as they could not avoid showing the mind of Maarten being involved in shaping (and distorting) the continuous self-experience that makes up the *fabula* of the experience of dementia—a *fabula* to which most of the novel fails to confine itself. Yet as the novel ends in a state where temporal distinctions and the distances between people and institutions are suspended (emblemized in the image of the hand, which can indicate both interpersonal and more impersonal modes of support), the ellipses there can be taken as constitutive elements of the basal self-experience that make up the *fabula*—an experience unconstrained by time, personality, and containing the weightlessness of lyrical moments of relief. It is these latter moments, I want to suggest, that the final ellipses I quoted above instantiate and that the novel leaves the reader with once the dynamics of self-reflexivity have finally collapsed into a form of life that finds itself sustained by the formal stabilities of institutions of care. The question whether this is an adequate mimesis of dementia consciousness is rigorously unanswerable; it is ultimately also less relevant than the realization that *Out of Mind* is essentially

an attempt to discover or create a form for dementia, even if that attempt takes it outside the mind.

4. Relating the Gaps: B. S. Johnson's *House Mother Normal*

Experimental British novelist B. S. Johnson's 1971 novel *House Mother Normal* (subtitled *A Geriatric Comedy*) predates the 1990s-era turn to respecting personhood in dementia care, which makes it unsurprising that the novel's representation of dementia consciousness has been found problematic. Still, while its formally innovative engagement with the realities of institutionalized care and the representation of dementia consciousness do not convey straightforward lessons for contemporary caring practices, its negotiation of the affordances of form make it a relevant resource for the "affirmative instrumentality" Levine calls for in order to dedicate the humanities to mundane practices of sustenance and care. The novel consists of eight consecutive interior monologues of the inhabitants of a care facility for people with different degrees of dementia. Each of these monologues is preceded by a list of numerical indicators of the characters' capacities (sight, hearing, touch, . . .) and a CQ score—the number of correct answers to a series of ten standard questions for senile dementia ("Where are you now?," "What is this place?"; Johnson 2016: 6). The scores vary between 10 for the first character (seventy-four years old) and 0 for the last one (who is ninety-four years old), which signals that the monologues cumulatively chronicle a process of mental decay.

It is tempting to interpret the careful attention that the different monologues afford the interior lives of the characters as a humanizing corrective to the reductiveness of numbers and as affirmations of their humanity, but such a reading would overlook the novel's own criticism of such facile humanizing gestures as those formulaic questions. The novel offers this critique most emphatically through its sardonic depiction of the figure of House Mother, the character in charge of the facility, who uses her responsibilities as a license for sadistic and often disgusting practices to which she consigns the inmates—absurdist wheelchair duels, a game of "pass the parcel" involving her dog's excrement, and, at the climax of the book, an unsolicited striptease and act of bestiality. Crucially, House Mother's cruelty is couched in the rhetoric of a patronizing humanism in both the introduction and the closing monologue that frame the inmates' monologues: she insists the inmates are not really "inmates, cases, patients, or even . . . clients," but "friends," even "old friends" (Johnson 2016: 5); they live their "second childhood" and she knows that "what we imagine they want for themselves is not actually what they do want" (185, 193). In revealing

the detrimental effects of a malignant social psychology that fails to take seriously the agency of people with dementia, *House Mother Normal* in crucial ways anticipates Kitwood's critiques of engrained caring practices. At the same time, by conveying its critique of medical paternalism in such a sardonic and wry way, the novel conveys an anti-institutionalism (Connolly 2014) that, on the face of it, makes the novel a less than promising case for tracing the work of form.

Nor are the particular ways the novel depicts the consciousness of its characters very promising. Like a typical stream of consciousness, the monologues rely on repetition, sound effects, and broken syntax. Not unlike *Out of Mind*, the memories evoked hint at dysphoric contexts such as war, guilt, sexual abuse, and violence, and, very much like in Bernlef's novel, mental disintegration is evoked through many gaps and even full blank pages (Domsch 2017). Together with onomatopoeias, italicizations, and typographical variations, this gives the novel a radically experimental look (consider such lines as "oooooooooh, b u t i t ' s n o h e l p n o w," from the less radically experimental first half of the novel; 2016: 90). As in the case of Bernlef's novel, the progressive fragmentation over the course of the novel invites the reader to compare the lives of the patient-characters to the norm of a neurotypical consciousness (from which the novel starts, in *House Mother's* monologue), and to see the blanks as so many indexes of a failure to live up to that norm. In Lars Bernaerts' (2014: 297) words, "The gaps in the text are to be inferred as lacunae in [the character's] mind." The novel, it seems, is not interested in imagining a dementia-specific basal self-experience without metaperspectives. Instead, the novel chronicles a shift toward formlessness; in the final monologue before *House Mother* closes the book, which belongs to a character named Rosetta Stanton, we merely find isolated nonwords ("eofn," "sylfaen," "addien") sprinkled on almost empty pages (Johnson 2016: 165–66). Form, it seems, has disintegrated below the threshold of lexical articulation.

So why then consider *House Mother Normal* an interesting novel for thinking about dementia at all? As in *Out of Mind*, the answer lies in the novel's allegorization of institutions as form. The key, like in *Out of Mind*, lies in the novel's manipulation of blanks. The perforated textures of *House Mother Normal's* representations of consciousness, I submit, directly reference the institutional infrastructures on which the lives of people with dementia depend. Underlying the chaos and confusion of the different monologues, Johnson's novel is marked by a rigorous pattern. Every character is allotted the exact same number of pages, which span the exact same period of time. The part of a particular page always covers the same stretch of the evening. For the reader, this means that initially bewildering elements can

be filled in by consulting the corresponding pages of other monologues—which also means that the reader is invited to engage in the construction of a shared reality, of the space in which the lives on display are collected. In the first monologue (Sarah Lamson’s), for instance, references to a character “let[ting] the mop drop” and voices shouting “*Keep up the mop now, George!*” make little sense (23), but corresponding places in later chapters fill in further details (a sort of duel between George Hedbury and Sioned Bowen, whose wheelchair is pushed by Charlie, as we learn in the third monologue; Sioned Bowen’s strategy, which we learn in her (the sixth) monologue; and George Hedbury’s destitution in his own extremely elliptic monologue). What enables this work of construction—what, with Kornbluh (2019: 156, 13), we can call the novel’s “composed relationality,” its focus on “context coherency”—is the book’s rigorous regularity, its strict adherence to particular organizational patterns. This is the way, I argue, in which the novel formally allegorizes the work of institutions.

Countering its official anti-institutionalism, then, *House Mother Normal* puts forward a formal logic that redeems the institutional setting of the novel as what, in Levine’s (2015: 3) terms, “order[s], pattern[s], or shape[s]” the lives it collects—which is to say, provides them with a form and a continuity they cannot themselves provide. Different from *House Mother*’s malignant paternalism, the novel’s gaps invite readers to coconstruct a space where vulnerable lives can thrive and relate to one another. The novel’s formal project, then, oscillates between a radical reduction of consciousness (the focus of earlier interpretations of the novel) and an affirmation of institutional care as a compensatory site of continuity and sustenance. The novel describes old age as a certain loosening of form: it is “the time when the bearing surfaces of the joints begin to wear seriously, when the walls of the veins and arteries harden, when the nervous system loses much of its subtlety” (Johnson 2016: 198). It is invested in exploring compensatory formations to provide the support the body and the mind can no longer muster themselves.

That the novel’s project is a constructive rather than a mimetic one is evident from the nature of the monologues, which, especially in the first chapters, are too carefully crafted not to be read as (almost) dramatic monologues. As Lars Bernaerts (2014: 294) notes, *House Mother*’s dramatic and unreliable opening to the book (“You shall see into the minds of our eight old friends, and you shall see into my mind”; Johnson 2016: 5) infuses the monologues with an ironic and metafictional twist that affects “the illusion of authenticity associated with the mimetic evocation of minds.” So, if not a mimesis of the demented mind, what then? Bernaerts’ remark that the novel “foregrounds the constructed nature of fictional minds” (298) use-

fully begs the question what exactly the elements are that go into that construction. Bernaerts (295) corrects the critical tendency to read the novel as turning “inward and back to the past” (Mackrell 1985; Tew 2001) when he notes that the monologues also convey how the characters constantly interact with their environments. Indeed, as I argue, the novel explicitly invites the reader to try and construct the shared contexts in which the different interior monologues are located. This makes it possible to read the novel’s blanks as pointing radically outward, beyond the minds represented to the bodies and world in which they are embedded (Tynan 2020).

It is in this sense, then, that form plays a constructive rather than merely mimetic role; it is, in the novel’s own words, the institutional setting that provides “a framework within which to establish . . . [the people with dementia’s] own special personalities” (Johnson 2016: 198), a framework it explicitly analogizes to the book’s structure (“the framework of twenty-one pages per person”; 204). In keeping with Levine’s case for form, this formal work is also a work of sustenance and care. Even when we are confronted with the highly elliptical stream of consciousness of the last inmate, readers know how to situate this minimal form of consciousness in social space and time, precisely because they can invoke the support of the preceding (and less elliptical) monologues. The blanks become a site of relationality—to other people with dementia, and, crucially, to the institutional regularity that connects them. Even if we read the concluding blank pages in the last inmate’s section as an indication that she dies, this is still a reality the novel’s structure can accommodate.

House Mother Normal underscores that, in the case of dementia fiction, Levine’s insistence on regularity and routine as the key aesthetic attributes of a literature committed to sustenance is incomplete. What emerges here (and in *Out of Mind*) is a particular economy of disruption and routine that positions the latter as an achievement required by the unavailability of the former. Levine (2021: 227) admonishes modernist orientations that valorize disruption and difficulty for promoting a quietist “humility in the face of a complex world no one should try to master.” Dementia fiction reminds us that often complexity is real, and surrendering mastery is often an attempt to make way for different ways of offering sustenance and continuity to the lives who are most afflicted by that complexity. In this respect, it is significant that *House Mother Normal*’s commitment to institutional care is realized through the novel’s form, and not through its affective or ethical commitments. The novel’s ethical condemnation of House Mother, as a stand-in for a particular institutional ethos and arrangement, is unmistakable, and it materializes in an investment in negative affects—disgust, awkwardness, guilt, outrage. If the novel’s commitment to institutional arrangements

overrides these ethical and affective choices, the novel also declares such affective and ethical issues to be strictly irrelevant to the political work of affirming the need for adequate infrastructure. This is not to say that the work of humanizing people with dementia and making them available for readerly empathy is irrelevant; it is to say that dementia fiction's commitment to form is primarily engaged in a political project, not an ethical or affective one.

5. Conclusion: Refusing Formlessness

Viktor Shklovsky's 1917 essay "Art, as Device" remains one of the most resonant statements about the affordances of literary form. Shklovsky (2015: 162) famously situates the power of literature in its capacity to de-automize perception: "The device of art is the 'estrangement' of things and the complication of the form, which increases the duration and complexity of perception." For recent advocates of the politics of form like Kornbluh and Levine, Shklovsky constitutes a wrong turn in the history of formalism: for Levine (2021: 240), because he scorns routine and predictability; for Kornbluh (2019: 13), for the very different reason that he opposes "literature's unique propensity for abstraction," as he emphasizes literature's capacity to restore the vivacity of things. Shklovsky's formalism, by these accounts, makes it impossible to build things up; it remains committed to demolition and, in Kornbluh's (2019: 17) terms, exemplifies a tendency to "idealize formlessness as political virtue."

This essay subscribes to Levine's and Kornbluh's politics of form (even if I restrict my understanding of form to what readers can realize in their relations to texts), but not necessarily to their aesthetics. As the case of dementia fiction shows, estrangement is also part of the work of form. For Shklovsky, crucially, estrangement is *not* a breakthrough to formlessness, but the work of formal innovation; literature is a struggle for form, not a stage for the eruption of formlessness. It is a mistake—and it is also Shklovsky's mistake—to misread such innovation as mere disruption and as inimical to sustained change. In the passage above, Shklovsky links "the complication of the form" to the increased "duration and complexity of perception"; he continues by noting that this process of "perception" is "an end in itself" that "must be prolonged." Must, but cannot: Shklovsky's (2015: 162) essay continues by recognizing (and bemoaning, to be sure) that poetry inevitably turns to prose, "seeing" to "recognizing," concrete to general, sensation to image. Given the impossibility of aesthetic perception to function as only "an end in itself," formal innovation is more than a fleeting moment of escape from form; it inevitably sediments as a novel

constellation of life and form, reality and construction—or, indeed, of human life and the infrastructures needed to sustain it.

Against Shklovsky's official (but incoherent) case for artistic autonomy, Levine (2021: 234) calls for a particular "kind of means-ends thinking," not the vaunted kind that merely uses literature for a goal external to it and "fall[s] back into the trap of instrumental rationality," but one that promotes "collective continuance [as] an end that is also an ongoing means." In a 2003 essay, W. J. T. Mitchell (2003) advocates a "commitment to form" in terms that also embrace such a commitment's capacity to blend means and end: if it often seems that form belongs "to the merely instrumental sphere of means" (322), formalism's principled attention to *how* to achieve emancipatory, progressive political goals is in fact "central to any notion of right action" (324). Retrofitting that juncture of means and end to the case of dementia fiction, what emerges in my readings of *Out of Mind* and *House Mother Normal* is an economy of rupture and routine that we can read both as an end in itself—as these two works' innovative formal projects—and as an ongoing means to imagine a mode of life that is marked by that particular rhythm—a rhythm that absorbs formal jolts without abandoning them to formlessness. Indeed, it is by *reading for form*—which means taking seriously both (dementia consciousness's) challenges to form and the story's allegorization of institutions as forms—that this essay has shown these novels making a case for the need for institutional supports to provide lives of people with dementia with the sustenance and continuity they cannot foster themselves. It has also shown, I hope, that a critical posture of affirmative instrumentality does not constitute a radical break with the customary protocols of literary criticism. Indeed, most of my energy has been invested in the re-interpretation of two rarified, fairly experimental works, and in meta-critical reflection on the affordances of form (a process in which I have admittedly bracketed historical contextualization that situates the works in relation to historically available conceptions of dementia; see especially Zimmermann 2022 for an account of *Out of Mind* in the context of the "Alzheimerisation" of dementia). Affirmative instrumentality, I submit, is primarily a commitment to the multiple operations of form, rather than to a particular style. In the project of sustaining human life, the choice between disruption and routine is one we have never been able to afford.

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