

CHAPTER 7

Slow Emergency
*Life Writing, Dementia, Gender, and Care**Rachel Adams*

When sixty-four-year-old feminist psychologist Sandy Bem created a file called “memoir” on her computer, she believed it was already too late. Earlier that month she had been diagnosed with amnesiac mild cognitive impairment, a prelude to Alzheimer’s. She wrote in her journal of “a mind that could be so alive one moment with thought and feeling building toward a next step and then someone erases the blackboard. It’s all gone and I can’t even reconstruct what the topic was. It’s just gone. And I sit with the dark, the blank.”¹ To Bem, who had always equated her sense of personhood with intellect, autonomy, and self-expression, the diagnosis was a death sentence. She determined to end life on her own terms, when her cognitive changes amounted to a loss of the self she once had been. As her condition progressed, Bem made adjustments that allowed her to participate in, and continue to enjoy, many activities with considerable independence. Although she and her husband had separated fifteen years before, he proved to be a loyal and attentive caregiver. When their daughter had a child, Bem became an unexpectedly doting grandmother. Nonetheless, Bem was determined to take her own life and, five years after receiving her diagnosis, she did.

The fact that Bem could still do, and take pleasure from, some activities did not strike her as sufficient reason to keep living, since she believed her critical faculties essential to her identity. Her decisions were consistent with the version of feminism she endorsed, one that prized independence, autonomy, and self-expression above all else. Her feminism gave her tools to question the patriarchal narrative in which women are predisposed to be passive and dependent, but it did not prompt her to question an equally powerful narrative that sees dependency as a tragic erasure of personhood, meaning that her diagnosis could only signal a slow and costly decline into oblivion.

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The fact that Bem was a woman and a feminist scholar provides an occasion for further consideration of the gendered dimensions of Alzheimer's. These are significant, given that the majority of those with Alzheimer's, as well as those who care for them, are women. Feminist theory has developed a powerful arsenal for challenging ageism directed toward the female body and the social devaluation of aging women.² It has been less adept at reframing narratives about dependency and cognitive change that inevitably come with advanced age and are amplified by age-related Alzheimer's. Nussbaum, for example, affirms aging by insisting on her continued intellectual energy, productivity, passion for fitness, and opera singing. Perhaps age would be anticipated with less dread and resistance, Nussbaum claims, if people didn't assume it went hand in hand with weakness and incapacity.³ While there is nothing wrong with her efforts to preserve health and vitality, the truth is that most, indeed eventually *all*, people who live long enough eventually do become more frail and more dependent. As long as age-related dependency is associated with loss of value, dignity, and personhood, the prospect of growing old will be greeted with anxiety and denial, and those resistances will take form according to gendered scripts about vulnerability, dependency, and care.

In what follows I consider how Alzheimer's narratives written by and about women are using literary forms to explore the relations among gender, personhood, and care. As alternatives to Bem's grim path, these accounts highlight the limitations to our current ways of imagining the gendering of age-related dependency and offer ways of thinking otherwise. I am particularly interested in how narrative portrays the temporalities of dementia; how individual narratives manage the formal challenges of representing a self that is in the process of being irrevocably transformed; and how, in the bleakest situations, caregivers and receivers find glimpses of unexpected intimacy, compassion, and interconnection. The term "slow emergency" in my title describes the temporal experience of having and caring for someone who has dementia. It is inspired by Elinor Fuchs, who calls the period of her mother's Alzheimer's "the Emergency," using a word that typically connotes a sudden and acute crisis to describe a situation that unfolds over almost a decade.⁴ A "slow emergency" is a situation of extreme magnitude and urgency whose full extent unfolds only gradually. This is akin to Rob Nixon's concept of "slow violence," which describes the problem of environmental collapse occurring over many generations. Of particular value is Nixon's exploration of inventive strategies used by authors and artists to represent crisis within a time frame too vast and slow-moving to be apprehended by typical narrative means.⁵ While Alzheimer's

extends over months and years, not generations, it follows a similar process of becoming apparent via gradual revelations rather than a single dramatic catastrophe, while ultimately being no less urgent and calamitous.

7.1 The Gray Tsunami

Bem's story is tied to a broader collective story about the graying of developed nations and the demographic shifts it portends in the early twenty-first century. At the start of the millennium, the US Census identified a 38 percent increase in the number of Americans over age eighty-five, and the highest-ever median age of 35.3 years.⁶ Since then, predictions of a gray century have become more extreme. Where in 2010 there were sixteen people over age sixty-five for every adult between ages twenty-five and sixty-four, by 2035 the United Nations estimated the number would be twenty-six.⁷ A 2015 report predicted that the elderly population of the United States would double by 2050, and that the number of "oldest old" (age eighty and up) would more than triple.⁸ While the AARP hailed this data as evidence of improved healthcare, rising standards of living, and better nutrition,⁹ other commentators described it as a "gray tsunami," a looming crisis of global proportions.¹⁰ The problem they saw hinged on a dramatic shift in the "dependency ratio," the proportion of dependents to wage earners in the world's population. The care required by the larger numbers of old people would outstrip what healthy, able-bodied adults could provide while still maintaining current levels of productivity. As Bem well understood, the crisis is thus not with aging itself, but with the growing dependency it entails, and the threat care poses to the security, well-being, and productivity of the world's more youthful populations.¹¹

Alzheimer's dementia is central to the alarmist discourse of the "gray tsunami" because it represents the outer limits of care: progressive and prolonged states of dependency that stretch both givers and recipients to maximum capacity. Alzheimer's is also deeply gendered. Women are far more likely to be diagnosed with Alzheimer's than men, a statistic only partially explained by their greater longevity. In addition to genetic factors, researchers observe that being a caregiver for someone with dementia is itself a strong risk factor for developing Alzheimer's. An estimated 60 percent of Alzheimer's caregivers are women, many of them already charged with caring for children or other dependents.¹² When women are not able to care for themselves or their kin, it is usually other women – often low-paid immigrants of color – who take their place.

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Life writing about Alzheimer's brings into focus such challenging social dynamics as the unevenness of caregiving cycles, the differences between caring for an elderly person and caring for a child, and the race, gender, class, and regional determinants of elder care. But equally important, and far less remarked upon, are the aesthetic dimensions of care narratives, how literary forms contribute to reimagining the experience of having and caring for those with Alzheimer's. In his study of Alzheimer's, *The Forgetting*, David Shenk writes, "while medical science gives us many tools for staying alive, it cannot help us with the art of living – or dying. Life, in its precious transience, is something we can only define on our own terms."¹³ Shenk's characterization of living and dying as "art" makes literature a key player in apprehending the "precious transience" of life, an instruction manual for how to maintain personhood in the context of bureaucratic healthcare systems and social institutions devoted to productivity, independence, and wellness.

The most prominent feature of Alzheimer's narratives is their attempt to restore the history, motivations, and personhood of individuals otherwise reduced to a set of symptoms, complaints, and deficits. Some argue that it is useful (and perhaps even comforting) to understand dementia in terms of "retrogenesis," progression back through the developmental stages of youth, childhood, and infancy. Yet such yardsticks are also horrifically infantilizing. Life narratives are a reminder that people with Alzheimer's *are not* children but persons whose bodies and minds are shaped by decades of use and experience. Moreover, narrative can capture the particular temporalities of an Alzheimer's diagnosis, which may be uneven, recursive, or precipitous, all of which are features of "slow emergency." Stories of Alzheimer's are also deeply concerned with futurity: because of its prolonged and erratic unfolding, Alzheimer's forces the diagnosed and his or her intimates to ponder future dependency and the possibilities and resources available for an extended period of care. In what follows, I consider narrative strategies used by authors with Alzheimer's and their caregivers to depict slow emergency and other dementia temporalities.¹⁴ Too often, the needs of caregivers and those of dependents appear to be competitive and irreconcilable. Our understanding of what is required to live successfully with Alzheimer's is limited if we listen only to stories of those with the diagnosis, or only to their caregivers. Examining these narratives in juxtaposition will provide opportunities to identify formal and thematic concerns shared by givers and receivers, as well as key knowledge each vantage is best situated to produce: the unsettling of traditional chronologies and experiences of temporality, the profound

discovery of interdependency and its limits, the gendered expectations around care, and the scandal of paid caregiving. That said, there are limits to what individual narratives can offer. I conclude by considering how they gesture to exclusions and the unvoiced perspectives that lie beyond.

7.2 Writing Alzheimer's

The concept of an Alzheimer's memoir is something of a paradox in that primary symptoms include loss of memory, whereas a memoir is, by definition, a work of reminiscence. While all memoir approaches the past selectively, the author with Alzheimer's employs a genre devoted to recounting the self at the very moment the self threatens to dissolve. This conundrum is precisely what makes Alzheimer's narratives interesting. Not only do they require a more creative and less individualistic definition of memoir than conventional understandings of the genre, but also a more nuanced understanding of what it means to live with Alzheimer's. Memoirs by women are especially attuned to the gendered experience of becoming-dependent in the face of social scripts that position them as caregivers. They wrestle with how to maintain dignity in the context of growing dependency, fear of burdening others, and the uneven distribution of care work.

Gerda Saunders's memoir, *Memory's Last Breath*, addresses these concerns with particular insight. Saunders is typical of Alzheimer's memoirists in that she writes about and from the initial stages of disease, which leaves her with considerable capacity to remember and articulate her experiences. But the early onset of her disease, which was diagnosed when she was sixty-one, is unusual. Saunders's relative youth and vigor prompt her to emphasize living on over fatalistic succumbing. Her story denaturalizes the myth that Alzheimer's is an expected complication of the aging process, as well as the ageist biases that often inform treatment. If she is not a particularly representative figure, Saunders's story is a reminder that there is no one way to live with Alzheimer's dementia, and that age and dementia do not necessarily go hand in hand.

Like Sandy Bem, Saunders is a feminist scholar, and she was Associate Director of the Gender Studies program at the University of Utah at the time of her diagnosis. Indeed, Saunders authors precisely the kind of auto-ethnography that Bem's doctor must have imagined when he urged her to write in the early stages of her diagnosis. Saunders's subtitle, *Field Notes on My Dementia*, bespeaks her determination to approach her experience with the curiosity and openness of an anthropologist. Calling her book "field notes" highlights its preliminary nature, its intention to capture the rough

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edges of experience as it is perceived and recorded. “Field notes” also describes sections of the book that read like short journal entries and are interspersed with more extensive reflections on her diagnosis and narratives about the past. An Author’s Note emphasizes ~~her~~ (the?) extensive collaboration with editors, a literary agent, and feedback from early readers. Of course, such thanks are de rigueur. But in a book so shaded by fear of dependency, they also make the point that support networks can be generative as well as constraining; all published books are collaborative projects, even if only one individual is credited as author.

Perhaps because she grew up in apartheid South Africa, Saunders is more attentive to the racialization of illness and dependency than many other Alzheimer’s memoirists. She writes of growing up in a family that defined personal worth by intellectual ability, and in a culture that saw it as an attribute of white supremacy.¹⁵ Writing about her country of origin is not just a way of preserving a self that threatens to fragment and vanish, but also to record memories of racial injustice out of concern that disease will cause her past to fade into an idyllic blur. She remembers, for example, picking up her children from school and seeing the Black nannies segregated from the white mothers. The law of apartheid forbid children and grandchildren of those live-in caregivers from residing in the homes of white employers. While caring for white children, Saunders writes, they “had to send their offspring to townships or ‘homelands’ to be raised by grandmothers or aunts and attend substandard schools” (124). In South Africa racial segregation was supported and maintained by law, but Saunders recognizes how poverty has similarly divisive effects in the United States. Forced to give up her driver’s license, Saunders rides the bus. Concerns about her own loss of independence quickly fade as she becomes aware of an underclass of disabled and people of color:

[N]othing like being one of the elite on the bus who are not toothless, homeless, in a wheelchair, or on oxygen to take my mind off myself. Nothing to make my troubles seem trivial like the disproportionately large number of African Americans, Native Americans, and Hispanics awakening my racial privilege. (161)

Even as she confronts the grim realities of her diagnosis, Saunders recognizes how her troubles are mitigated by racial and economic privilege not shared by other passengers.

Gender is also an important aspect of self that is affected by Saunders’ diagnosis. Like many women, she finds value and purpose in being a caregiver. She raised her own children and cared for her mother, also

diagnosed with early-onset Alzheimer's. At the time of her diagnosis, Saunders is helping her neighbors, Bob and Diane, who are managing multiple challenges, including a son in assisted living following a brain aneurysm, and a series of strokes that left Bob with extensive physical and cognitive impairment. Saunders describes Diane's grueling routine in considerable detail:

Since Bob's first massive stroke, Diane has spent at least twenty hours a day in the house with a husband who has no conversation and does not know the difference between day and night, making for an erratic sleep pattern. . . . Bob constantly needs help with toileting, bathing, dressing, feeding, and staying safe. Diane stepped into this demanding caretaker role directly from her job of cleaning houses three days a week, an activity and income she had to give up three years ago when she became a full-time caregiver. Other than the approximately eight hours per month that she has free to have her hair cut or go to her own doctor appointments, she is constantly in charge of Bob in a house with double-locked doors to prevent him from indulging his *wanderlust*. (154)

Saunders dwells on the time and physical stamina required for Bob's care. In the absence of a support network, the labor falls almost entirely on Diane, leaving her frustrated and lonely. Diane's plight seems especially unjust given that she was forced to retire from paid domestic service into the unpaid job of tending to her husband. Saunders is bolstered by recognizing Diane's need and providing her with respite. But there is a more fearsome aspect to this description, since Saunders also identifies with Bob and realizes that one day she may place a similar imposition on her loved ones. When forced to give up driving, she laments that it will hamper her ability to be helpful, but also that it represents an unwelcome shift toward being a recipient of care.

Saunders envisions the growing dependency predicted by her diagnosis with dread. She takes Bob as a negative model, fearfully contemplating the burden she will create for her family. "I can only guess at the stress that the utterly dependent and exceedingly self centered bundle of need that dementia will turn me into will provoke in [her husband] as my primary caretaker," she writes (187). Although she has benefitted from being a caregiver, Saunders is unable to imagine a scenario in which her becoming-dependent doesn't inflict suffering on others. Her future horizon focuses on the stress, exhaustion, and expense of caring for a person with Alzheimer's.

More affirmatively, *Memory's Last Breath* attends to the surprising unevenness of disease progression. Even as her daily life is punctuated by the indignities of confusion and memory loss, Saunders continues to reflect

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lucidly on her experiences and to write with striking coherence about her past. So great are the disparities between these registers that, at first, she wonders whether she has been misdiagnosed. But after finding numerous other stories where the newly diagnosed are accused of “faking” (37–38) she instead proposes a revised understanding of dementia. “The discrepancy between those failures [of short-term memory] and my preserved writing ability are part of my story, too” (26), she insists. Attending to what is salvageable, as well as lost, allows Saunders to concentrate on living rather than future decline.

Disease also has little effect on Saunders’s ability to experience sexual desire and pleasure. She offers the cautionary tale of seventy-eight-year-old Iowa state legislator, Henry Rayhons, whose children accused him of sexually assaulting his wife, convinced that their mother’s Alzheimer’s made her unable to consent to sexual activity even as she continued to express desire. Rayhons was tried for felony sexual abuse and acquitted of all charges (158). To Saunders, the Rayhons case exemplifies the tragic consequences of failing to recognize the unevenness of dependency, which may preserve the capacity for pleasure and desire, even as other functions are disabled.

One of the greatest formal challenges faced by the Alzheimer’s memoir is that it is motivated by a terminal diagnosis that will eventually lead to death. How to imagine the aesthetics of ending when the future involves total dependency, followed by death? Talk about death of the author! While death is a certainty for all autobiographers, the Alzheimer’s memoirist navigates a particular paradox in which the occasion for writing is the impending obliteration of the writing self. Somewhat surprisingly, Saunders turns to science for comfort. She takes on the role of amateur neurologist as she researches the medical literature on dementia and studies how her brain scans correlate with her symptoms. An MRI proves her confusion and forgetfulness are not caused by lack of will or weakness of character but from dysfunction in her brain. At the same time, the scan also confirms the unevenness of disease progression by providing more hopeful evidence of large areas of her brain that remain intact.

At a molecular level, science also allows Saunders to recognize a reassuring continuum between life and death. While the socially constructed self is individualistic, discrete, and finite, science envisions a more capacious *bios* assembled from elements recycled over the generations:

[I]mbrications, indeed, stand for the main purpose of my life: being connected, with honesty and integrity, to the mineral, vegetable, animal, astronomical, and cosmological worlds, particularly that infinitesimal subset

of the animal kingdom, my fellow humans, with whom I have in common, a wondrously complex brain that gives us access to the “truth of the Imagination.” (255)

This image of life interconnected at a molecular level adds meaning to Saunders’s title, *Memory’s Last Breath*. The “last breath” most obviously refers to loss of memory and the coherent personhood that accompanies it. However, breath is also central to Saunders’s vision of a molar continuum. “All my life I have sucked into my lungs molecules from not only the last breath of animals and people I have loved,” she writes, “but also from their exhalations at any of the moments I choose from their biographies” (255). Emphasizing continuity of lives over the rupture of an individual life, Saunders envisions the “last breath” of memory destined to be inhaled by others, becoming a part of them.

Becoming molecular provides Saunders with a comforting image of enduring beyond the reach of memory and self, but it also points to a future beyond narrative. With the departure of memory, a body remains to be cared for and sustained. The horror of an Alzheimer’s diagnosis is its promise to irrevocably transform the self, but also to burden caregivers with sustaining a body deprived of memory and capacity for narrative. The accounts of caregivers – usually adult children – dominate the life writing on Alzheimer’s, testifying to the grief, cost, and emotional strain of caring for an elderly parent, often while working and raising children. Such narratives fill a different function than those of the diagnosed, documenting the failures of current resources available to support people with Alzheimer’s and the ad hoc coping strategies developed by their families. They also document the wages of an ageist society that make it exceedingly difficult to contemplate, and plan for, future dependency. Caregiver memoirs provide an opportunity to relate the experience of slow emergency, but also to sustain the personhood of those no longer able to represent themselves in narrative. More generatively, these narratives share Jonathan Franzen’s acknowledgment that “Senility is not merely an erasure of meaning but a source of meaning.”¹⁶ They attest to the conflicted meanings generated by Alzheimer’s, which may simultaneously entail a cruel and undignified obliteration of the familiar self, and, in its absence, the creation of new opportunities for intimacy and connection.

Elinor Fuch’s *Making an Exit* acknowledges the full range of such meanings as her mother’s disease progresses. Her story consistently unsettles the gendered assumptions around care within the family. She dispels any notion that she takes responsibility for her mother, Lil, out of innate desire to

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nurture and protect, or an impulse to reciprocate maternal care she received. According to Elinor, Lil was an indifferent mother. Devoted to career and travel, she pressed her daughter into premature independence, left her in the care of others, and offered no help when Elinor struggled to balance her career with caring for young children. “I have put nearly a decade of my life into this emergency,” she thinks resentfully, focusing on opportunities lost while caring for her mother. “In that decade my daughters needed more attention, my work was retarded, friendships narrowed, and my last best years to remarry, at least actuarially speaking, expired” (157–158). Instead of perceiving herself as returning debts of care accrued in childhood, Fuchs sees caregiving as a burdensome expenditure of time and energy.

Among the most potent formal devices Fuchs uses to depict slow emergency is the catalogue. Long lists of needs, caregivers, treatments, expenses and supplies emphasize a mounting accumulation of burden, stress, expense. While catalogues have traditionally been associated with epic poetry, where they may describe an august genealogy, a gathering of important people, or collection of revered objects, Fuchs’s catalogues do not intend to elevate or impress but rather to connote a piling on of responsibilities, necessities, and material possessions. “If [Lil’s] memory is vacating the premises, I am overstuffed with it,” Fuchs writes:

I am the link to her internist, her cardiologist, her oncologist, her gynecologist, her dermatologist, her lawyer, her bank, her accountant, her insurance agent, her landlord, the IRS, the Social Security Administration, Blue Cross, Medicare, the Wadhwanis, and the helpers. I have left out her piano tuner, her dry cleaners, her hairdresser. The entries in my address book for Mother run to a dozen pages. I am her carapace, a crustacean of memory dragging my mother, my mother the drag queen, the two of us in a single shell. (92)

Care queers Elinor and her mother in requiring atypical intimacies and confounding gender roles. In this passage, Lil becomes “the drag queen,” a dead weight pulled along by her daughter’s efforts. In being responsible for all aspects of Lil’s care, Elinor is transgendered, burdened with the obligations of both a “traditional daughter” (92) and a “traditional son” (93). Things grow queerer as the catalogue details Elinor’s responsibility for the most intimate recesses of Lil’s fragmented and ailing body. Lil no longer remembers to remove her dentures, requiring Elinor to release and clean them. Elinor learns to change her mother’s diaper and, perhaps most disturbing, she discovers Lil wears a pessary which, when forgotten and untended, gives her “a raging vaginal infection” that requires “Someone [. . .] to insert a tube of antibiotics into Mother for the next seven days.”

7.3 “Aiiieeee! Not me, not me!” (93)

Her wailing response gets its own paragraph to signal revulsion-verging-on-hysteria at the prospect of ministering to her own mother’s infected vagina. If this were a different story, Fuchs might describe her mother’s suffering with compassion and tenderness, treating all aspects of her body with respect. After all, she is writing about the very bodily passage that once brought her into the world. In another version, she might protect her mother’s dignity by leaving the pessary out altogether. But Fuchs’ honesty is valuable in that it denaturalizes a daughter’s duty toward her dependent parent and makes visible the unromantic aspects of care that may elicit disgust, resistance, and denial.

In the face of Fuchs’ refusal, the question remains as to the “someone” who will insert antibiotics into Lil’s vagina. The catalogue mentions numerous medical specialists, professionals who tend to Lil’s hair, clothes, and piano, and more general care. The list reinforces how Alzheimer’s can drain energy and resources from all involved. Another describes just how many people are required to attend to Lil’s safety and wellbeing:

Mother can’t find her way from the seventh floor to the first without assistance, can’t dress without assistance, can’t go to bed without assistance, can’t make pee-pee without assistance, so in addition to twenty-four hour everything, Mother has two new nurses splitting the weekday job. Plus she has Olga and Gwen, the part-timers brought over from my seven-year pasted-together home-care system. Plus she has Ruth, who still helps with arrangements. Plus she has me. And she has her brother, Ed, who stops in at least twice a week. Everyone is exhausted. Now there’s assisted living for you. (2)

Lil’s needs are represented as constant, pervasive, and overwhelming. In its repeated use of the word “can’t,” this list emphasizes her limitations over abilities; its repetition of “in addition” and “plus” conveys the tiring accumulation of burdens.

There is a dark comedy to such accumulated details, but the overall effect is unavoidably negative. Yet Fuchs insists that there are also generative aspects to her experience. Despite being exhausted and frustrated, Fuchs appreciates newfound intimacy with the mother who had always seemed distant and unknowable. “You could admire her, enjoy her – as indeed she did herself,” she writes of her mother before the illness, “but you couldn’t exactly love her” (3). Once Lil becomes dependent, Elinor finds her easier to love, and even to enjoy: “Mother is eighty-four, I am in my fifties, and we are playing patty-cake. We are doing childhood all over

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again. For all I know we are doing so for the first time. We are having such a good time” (155). Hard as it is to be so needed, Fuchs recognizes those moments when dependency can be a source of pleasure and satisfaction. The confusing temporality of this passage doesn’t represent a simple regression or role reversal. Instead, meaning comes from uncertainty about whether they are experiencing a return (“doing childhood all over again”) or something entirely new. If there is a lesson here, it is *not* about recognizing the hard-won intimacies that come from attending to the basic needs of another.

Fuchs also finds aesthetic value in her mother’s cognitive change. “As Mother’s speech breaks down,” she writes, “I become interested in the floating hydrogen of the residue. I see Lil not only as a ‘patient’ and ‘sick,’ but as an artist, spinning the poetry of a private world, and I began to carry a little tape recorder to catch these exchanges” (109–110). There is no direct paraphrase for “floating hydrogen of the residue,” but this image suggests that Lil’s nonsensical speech emits a kind of buoyant gas reminiscent of balloons and water toys enjoyed by children. It would be easy to criticize this portrait of the demented person-as-poet for being overly romantic were it not couched within a larger narrative that directly addresses struggle, loss, and decline. Fuchs finds meaning and beauty through the eruption of unexpected creativity in a condition that seems otherwise relentlessly awful. Such rewards come only as Elinor adopts an altered vision of Lil as an artist of her illness; and of language as a tool for expressing sound and sensation as much as information.

Notably, such insights are available only within an environment designed to support, and even welcome, Lil’s changed cognitive state. Living on her own, Lil’s lapses in memory and understanding lead to chaos, and even danger. But in a space designed to accommodate people in her condition, Elinor can see possibility as well as decay: “In this setting [an assisted living facility], I think of Mother not so much as ill, but as an original, a zany, an artist, cha-chaing through the corridors, inventing a fractured language that would have excited Gertrude Stein” (123). Fuchs recognizes that the symptoms of Alzheimer’s, like many other illnesses and disabilities, are impacted by environment as well as the changing bodymind. Attending to the interaction of the bodymind with environmental cues, the caregiver assumes a more active role, collaborating in the creation of spaces that slow the impact of disease, and that emphasize the potential, rather than the limitations, of the person with the diagnosis.

Fuchs is well aware that there is only so much to be accomplished by environmental adaptations; eventually and predictably, disease wears away

her mother's body and mind. More surprisingly, in the late stages of crisis, Fuchs finds something like joy in her newfound interdependency. "It hardly matters now which of us the mother and which the daughter," she writes. "Taking care of as good as being taken care of. My job, to keep the little life aflame for just a while, to keep the little spirit in the world" (186). When Lil is most dependent her daughter unexpectedly perceives their relationship as most *interdependent*, recognizing a circuit in which giving care is as necessary and sustaining as receiving it.

Fuchs finds tenderness, joy, and compassion in the final stages of her mother's illness by acknowledging the humor, beauty, and something like joy, in a dementia aesthetic. Like Gertrude Stein, she finds value in words that are silly, nonsensical, chosen for the way they sound rather than their dictionary definition. Fuchs is also fully aware that she can experience these moments as beautiful only because she has been able to offload a certain amount of her mother's care onto others. As is true of Saunders, Fuchs comes to recognize how the manifestations of illness are shaped by a negotiation between social and bodily resources. The slow emergency makes it impossible for Fuchs to attend to her mother's many needs without sacrificing her own life and that of her dependent daughters. Care must be dispersed over an increasingly wide network of providers, almost all of them women of color. Fuchs' memoir focuses on her relationship with Lil as her mother's illness progresses. But the global reach of Lil's care network is apparent everywhere around the margins: the "Caribbean lady in a white uniform" (1) who works at her assisted living facility; a caregiver named Olga from El Salvador (5), and others from Ghana, Guyana, Russia, and Peru (100, 112); African Americans named Jeannine (91) and Margaret (137). A voice that answers the phone with a "West African lilt" (179). Fuchs acknowledges this network with gratitude. "It is astounding how many souls supported the enterprise of Lil," she writes, "how kind they were, how genuinely they cared for her" (99). Her memoir makes these caregivers visible and recognizes their contribution to Lil's sustenance. This means that, in addition to being a funny and moving story about the lately discovered interdependency of mother and daughter, *Making an Exit* is also, perhaps unintentionally, a portrait of the scandalous amount of labor and resources required, under current social conditions, to sustain the life of one relatively affluent white woman with dementia. Because of their different relationships to illness, Elinor Fuchs witnesses this injustice directly while Saunders senses it looming on the horizon.

Read together, *Memory's Last Breath* and *Making an Exit* attest to the contributions and limits of the Alzheimer's narrative. As a subset of illness

and disability memoir, these narratives introduce new voices and experiences to American literary history. They rewrite a script that describes Alzheimer's as a death of self, attesting to a prolonged and uneven living on as the self is transformed. They press at the bounds of genre, pointing to the limitations of the individually authored memoir, as well as the figure of the author, and the related assumptions about memory, reason, and autonomy it implies. They insist on the collaborative and gendered dimensions of care, showing the devastating effects of a society that devalues dependent persons and the work of those who sustain them.

Ultimately, the populations at the margins of these narratives – the bus passengers, nannies, healthcare workers, and cleaners – attest to their limitations, as well as the dire failures of developed nations, to care for all persons according to their needs. Even as they tell individual stories, Saunders and Fuchs are remarkably attuned to the collective, gendered labor that sustains a privileged class of dependents. It is perhaps too much to expect that those in the throes of their own slow emergencies would be capable of imagining more just alternatives to the inequities they observe. But their stories make apparent a population-wide slow emergency that will require radical rewriting of current narratives and the social systems they uphold.

Notes

1. Robin Marantz Henig, "The Last Day of Her Life." *New York Times*, May 16, 2015. Accessed at www.nytimes.com/2015/05/17/magazine/the-last-day-of-her-life.html.
2. See, for example, Ann Basting, *Forget Memory: Creating Better Lives for People with Dementia* (Baltimore: Johns Hopkins UP, 2009); Margaret M. Gullette, *Aged by Culture* (Chicago: University of Chicago Press, 2004) and *Agewise: Fighting the New Ageism in America* (Chicago: University of Chicago Press, 2011); Jane Gallop, *Sexuality, Disability, and Ageing: Queer Temporalities of the Phallus* (Durham: Duke University Press, 2018); Martha Nussbaum and Saul Levmore, *Aging Thoughtfully* (New York: Oxford University Press), 2017; and Kathleen Woodward, ed. *Figuring Age: Women, Bodies, Generations* (Bloomington: Indiana UP, 1999).
3. Saul Levmore and Martha Nussbaum, *Aging Thoughtfully*.
4. Elinor Fuchs, *Making an Exit* (New York: Picador, 2006).
5. Rob Nixon, *Slow Violence and the Environmentalism of the Poor* (Cambridge: Harvard University Press, 2011).
6. US Department of Commerce, *US Summary: Census 2000 Profile*. Accessed at www.census.gov/prod/2002pubs/c2kprofoo-us.pdf.

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16. Jonathan Franzen, "My Father's Brain." In *How to Be Alone* (New York: Picador, 2003), 25.