Pergamon

Journal of Aging Studies
17 (2003) 87–99

Journal of
AGING
STUDIES

Looking back from loss: views of the self in Alzheimer's disease

Anne Davis Basting*

18 Rutland Road, Brooklyn, NY 11225, USA

Abstract

This article examines the narrative construction of Alzheimer's disease in three autobiographies. Two of them use traditional linear structure, which demands a coherent, consistent "self" as narrator. The third is structured as a journal, allowing the reader to experience more fully the disjointed nature of the disease. All three create a clear sense of "self," which contrasts strongly the idea that Alzheimer's disease entails a loss of "self".

Keywords: Autobiography; Alzheimer's disease; Self; Narrative; Memory; Identity

---

> This force of my memory is incomprehensible to me, even though, without it, I should not be able to call myself myself.—St. Augustine (in Olney, 1999, p. 233)

1. Introduction

Alzheimer's disease can be a tragedy for its victims and their families, a tragedy of proportions that seem surreal until its all too vivid physical, emotional, and spiritual realities set in. However, Alzheimer's has also become something much more than the disease. It has swollen into a fear that permeates the cultural consciousness of the United States. It materializes in the form of jokes when people of any age forget their keys: "must be early

---

* Tel.: +1-718-693-0102.

E-mail address: basting@igc.org (A.D. Basting).

PII: S0890-4065(02)00092-0

Alzheimer's" or "I'm having a senior moment." That fear also manifests itself in descriptions of the disease as an economic and demographic nightmare awaiting us in the twenty-first century and in citations of the growing billions spent on health care and the projected 10 million additional sufferers over the next 30 years.

These fears tap a common source, which is that people with Alzheimer's lose something of enormous value in American culture, their individuality—their "selfhood." This is certainly a legitimate fear. In my interviews with personal and professional caregivers for people with Alzheimer's, all of them said they fear the disease. I add myself to that list. However, what is at the root of that fear? Is it the symptoms of the disease itself? Or the world of the disease—the attitudes and behaviors of others toward the disease—that accompanies it?

Understanding how Alzheimer's is perceived and represented can help interrupt and change the experience of the disease for those who suffer, those who anticipate suffering, and those who care for its victims. Understanding the depiction of the self in the crisis of Alzheimer's can also teach us the meaning and value of the "whole" self. Exactly how does one achieve a "self?" Who *are* we without memory? Is a "self" possible when the ability to construct narrative through memory is broken?

These questions certainly have long and rich histories in multiple disciplines, from philosophy and ethics to psychology (Holstein & Gubrium, 2000). As a scholar of performance studies, I approach these questions by reading the cultural context of performances of the aging self. In this study, I look at three autobiographies by people with Alzheimer's disease. How do these texts articulate a self in the midst of a disease that has been described as a funeral before death? What are the implications for our understanding of the self outside of the disease?

Autobiography is a contested term for these works. Thomas Couser (1997) would distinguish them as "illness narratives," personal accounts that focus on the illness itself, rather than the whole life of the author. Arthur Frank (1995) might prefer to categorize one, if not all of them, as "chaos stories" and not narrative at all. For Frank, "if narrative implies a sequence of events connected to each other through time," the breach of time in chaos stories would disqualify them from being called narrative (p. 98). I have chosen to call them autobiographies in order to emphasize their unique authorship. There are many illness memoirs (Couser's term) in which an adult child or a spouse shares the trials of caring for someone with Alzheimer's disease. There are only a handful of published texts in which the primary author is the person *with* the disease.

The three tell quite exceptional tales. The narrators of Robert Davis's *My Journey into Alzheimer's disease* (1989), Diana Friel McGowin's *Living in the Labyrinth* (1993), and Cary Smith Henderson's *Partial View* (1998) all received early diagnosis and entered the disease at a relatively young age, a condition known as "early onset." McGowin was just in her forties when her symptoms first appeared, Davis was a vital 53 when he preached his last sermon, and Henderson was just 68 when the disease rendered him mute.

All three of the autobiographies reveal enormous bravery and strength of spirit. The authors' aims are to guide fellow travelers in Alzheimer's through the many pitfalls they encountered. They do not aim to be literary texts, and so I do not address them as such.

Instead, following the structure of the texts themselves, I look at how the texts worry over and create a sense of selfhood in the midst of its perceived loss.

2. "My friend"

In *Living in the Labyrinth*, Diana Friel McGowin (1993) begins her story before diagnosis, when frequent episodes of confusion and lapses in memory force her to keep lists to order her busy life as a legal assistant, a mother of three children (with one still at home), and a wife in charge of household finances. Her own good humor and defiance are echoed in her family's responses to these episodes. They tell her to pull herself together or laugh as though she was doing a comic routine of absentmindedness. The narrative continues in staccato paragraphs that weave a chronological tale of growing confusion.

Although McGowin describes the symptoms of Alzheimer's, she does so in language cleansed of the disease—spelling, grammar, and memory of dialogue and events are pristinely intact. For example, in the opening chapter, McGowin tells of suffering a dizzy spell at a family picnic that left her language slurred. In relaying the story, she represents her normal speech in the text, only to have a relative tell her she sounds like she is drunk. The device has two effects. First, the reader sees the event through McGowin's eyes, unaware of her own garbled speech. Second, the narrative masks the disease. We witness the disease described, but not performed.

McGowin's is a story of fierce independence, denial, depression, acceptance, and, always, a lingering defiance. She takes on the mantle of the disease alone. She assumes that her husband, from whom she has become emotionally estranged, and her children, who have been dependent on her as both children and adults, will not be able to handle the diagnosis. So she keeps working, keeps driving, and keeps silent about her diagnosis as long as she can.

Under pressure from a friend, she goes to see a neurologist the day after her fall at the family picnic. "I loathed his habit of referring to me in the first person plural we . . .," she writes of her first neurologist, who excuses her symptoms and tells her to "keep her nose clean" (McGowin, 1993, p. 12). Finding a doctor who will treat her with respect and honesty becomes her mission. When she finally finds a suitable doctor in chapter 4, her fears relax into comfort with her confusion. After her doctor praises her assertiveness and strength of spirit, she is so happy that she mistakes a closet for the office door as she leaves. Rather than be embarrassed, she and the doctor are able to laugh at the incident together.

McGowin's fighting spirit continues throughout the narrative. "I want to know everything!" she exclaims when the doctor asks if she would like the diagnosis confirmed with an MRI (p. 35). Yet her denial also persists. Even with the diagnosis confirmed, McGowin keeps her silence and maintains her life relatively unchanged. Still afraid of her family's reaction, she reaches into her past for confirmation of who she was, of "the real Diane Friel" (p. 35). In her search, she corresponds with and then visits several friends from high school.

In chapter 6, McGowin searches her past, hoping to reinforce who she is by remembering who she was. McGowin's tales of reunions with hometown friends are the only place in the narrative where the disease appears performed rather than described. Until this point, the stories of becoming lost while driving and while in the hospital, of laying in bed all day with the curtains drawn to calm her paralyzing fears, are all told in seamless grammar by a strong-willed and good humored, if a little fearful, narrator. After searching through old yearbooks and drifting through memories of childhood, she decides to contact two old friends, Marie and Kurt. Again, she decides to keep her condition to herself, hinting only that she is having "some troubles." When McGowin visits Kurt, her embellished descriptions of him, in contrast to her self-portrayals, betray a growing sense of paranoia. She sees Kurt as a "Musketeer of valor" (p. 61), while she worries constantly about exposing her own fading faculties. Her paranoia grows in chapter 8 when she attends a class reunion and states flatly: "I was certain they had not liked me" (p. 79).

In chapter 7, McGowin addresses her increasing difficulties, which have been relatively absent from the three previous chapters, "Life had become an improvisational theater," she writes (p. 64). Her neurologist finally convinces her that she must stop working. Nearly 10 years after her symptoms first appeared, she calls a family meeting to discuss her diagnosis. However, she is too embarrassed to tell them she has stopped working, although it is clear they already suspect it.

Also in chapter 7, nearly halfway into the book, McGowin first hints at how the book itself came about. Sensing McGowin's deep frustration over her inability to work, her doctor encourages her to write about her experience with the disease: "He said I should continue to write, whether good, bad or indifferent. It was an outlet, and a means of keeping my brain cells alive" (p. 72).

The remaining chapters delve more deeply into McGowin's fears, and the unique symptoms of the disease. Again, her approach is good humored and bold. In chapter 10, she talks about her increased libido and her awkward exploration into how to satisfy it. A dear friend is surprised—not that McGowin asks her about masturbation, but that McGowin, well into her fifties in this chapter, does not know how to do it.

As McGowin reveals more and more confusion in the later chapters, the disjunction between the form and content of the autobiography becomes more pronounced. The chapters do get shorter, but McGowin continues to depict dialogue verbatim and to write in full and flowing sentences. For example, in chapter 13, "Ebbing Tide," McGowin writes of visiting her father in the hospital. She refuses to tell him about her disease, out of fear that his condition would worsen. Then sadly, the panic induced by the mazes of hospital hallways prohibits her from visiting him at all. And in chapter 14, she openly addresses her fears; the main one being that her husband will not be there for her. The final chapters relay McGowin's acceptance of loss, her persistent humor, and the vividness of her memories of the past.

McGowin is able to articulate quite clearly the contradiction between her own feelings of self-worth and the depletion of her cultural value as a victim of Alzheimer's: "If I am no longer a woman, why do I still feel I'm one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk, against my skin? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone!" (p. 114). I find her eloquence here almost disturbing. She fully captures the frustration that I have seen in the eyes and behaviors of people more advanced in the disease than McGowin. However, when those same people reach the middle to late stages, uttering a simple sentence, let alone such a complex one, would be impossible.

Finally, in the epilogue, some of the discrepancies between the book's form and content are elucidated. The Epilogue is credited to both McGowin and her husband, but the form, the narrative "I," remains the same in tone and spirit. For the first time in the book, "McGowin" talks about the process of writing and the difficulty she had letting go of narrative control:

> The biggest step my husband made was when he volunteered to master my little word processor to aid me when, or if, I lose the ability to operate my best means of communication with the outside world. So jealous am I of my little word processor friend that at first I only let my husband practice on an old broken-down one we owned. Nothing must happen to "my" friend, the word processor. It acts as my memory. It spells for me. It even corrects my grammar . . . sometimes. It never tells me to speak faster or to slow down. It permits me time to think. It permits me corrections. (pp. 124–125)

The joint "I" in the final chapter can be read in several ways. On one level, it reads as a happy ending to a tragic tale. McGowin's husband, whom she feared might abandon her, instead stays to support her and help maintain her identity. On another level, it calls into question the reliability of the "I" of the previous chapters. Was it really McGowin? Was it also her husband? To what extent?

Diana Friel McGowin, honor society student and all-around good girl from Cleveland, mother of three, manager of a law office, wife to Jack McGowin, and friend to many, defines her "self" in several ways. She uses the narrative "I" and her memory to create a chronological and consistent pattern of independent thinking and actions. She is a funny, independent thinker from her earliest memories on through her determined search for a doctor who respects her. She is so afraid of becoming dependent on her family that she keeps the diagnosis from them and suffers alone for nearly 10 years. She defines herself heavily on her usefulness to society and has a heightened awareness of her loss of social value when she must stop working—so much so that she replaces her paid work with writing the memoir, in hopes that it will be of use to others going through the disease.

3. The sun and the moon

Robert Davis's (1989) autobiography quickly establishes its unique mission and framework. A deeply religious man, Davis shares his journey into Alzheimer's disease in the hopes that it will "give some new insights into the confused, fearful mind of the Christian with Alzheimer's" (p. 16). The earliest of the popular press autobiographies by people with Alzheimer's, Davis's text also aims to help the millions of people concerned with Alzheimer's, for whom "little is written to help them understand or communicate." "Perhaps understanding the 'blackness' and 'lost' feelings," writes Davis, "will help families to be more understanding of the unreasonable actions they must deal with" (p. 17). For Davis, "sunlight" is the peace of his faith in Jesus ("son light"). Moonlight, on the other hand, is his loss of faith and the despair and paranoia the disease inflicts upon him.

Davis and his wife Betty are more up front, and a little more conflicted, about the shared narrative "I" in the book than McGowin. The dedication is to "our good friends." The copyright is owned by Betty, yet the book attributes authorship solely to Robert Davis. In the prologue, the narrative "I" that we assume to be Robert explains a writing process that includes writing, editing, revision, dictation, and transcription:

> Last September as I began to outline thoughts for this book, I was able to write them out. Although many words were missing, and many sentences unclear, Betty, my wife for 29 years, was able to decipher my intent and type it into the computer. Then together we read and discussed until I felt sure my feelings were recorded. Chapters 1, 8, 9 and 10 were written this way. By January, I could no longer type a complete thought or keep my head together to write out very much, so I rented a Dictaphone and wrenched Chapters 3, 4, and 5 this way. Chapter 7 became so disjointed that we had to take the paragraphs of my description of the physical aspects and let Betty rewrite them. Chapter 6 and the Epilogue are Betty's alone. (p. 18)

Like McGowin's *Labyrinth*, Davis's text is cleansed of any evidence of the disease in the form of the writing itself. Instead, Davis's symptoms are described rather than enacted. The prologue even marks this absence, when Davis writes that "we [he and Betty] have laughed at the many paranoid paragraphs that she has removed as we felt there was no need to so vividly illustrate some of the symptoms I describe later" (p. 18).

Unlike McGowin, Davis departs from strict chronological structure. He begins chapter 1, "From Sunlight to Moonlight," with two parallel tales. In the first, he has just finished his most demanding, most rewarding day of work of the year, preaching the Christmas Eve service. His reflections on his success with a growing congregation are countered by the following story, in which he regretfully preaches his last sermon just 1 year later. The "I" of the narrative, which is post-retirement, post-diagnosis, and pre-complete dependency, sets out the aims for the book in this first chapter and then takes the second, third, and fourth chapters to back up and tell the story of how he got to this moment. Chapter 5 returns us to the present moment and his yearning to come to terms with suffering: "I want to leave the message that God's healing power does not always remove physical suffering. God has ways beyond our comprehension, and sickness and pain are sometimes part of these ways. The important point is that God is able to heal physically. But whether or not he chooses to heal the physical body, he always heals the spirit of those who surrender to his will" (p. 64).

Betty's voice appears (overtly) in chapter 6, sharing research she compiled on the disease and the challenges of and approaches to care-giving. Her tone is thoughtful and kind, but she openly acknowledges the enormous difficulties of being a primary caregiver for someone with Alzheimer's. While Betty's narrative tone is distinct from Bob's, which is more philosophical, Betty links herself to his narrative by using a metaphor that Bob had established in chapter 1: "Obviously, as the patient sinks more and more into the moonlight, or drifts out to sea in the fog, only the very best and most caring of his friends will bother to spend time with him" (pp. 81–82).

Again as in McGowin's *Labyrinth*, the fact that Davis's narrative has been cleansed of the disease becomes more apparent as the book—and the disease—progress. In chapter 7, "The Abnormal Changes So Far," Davis's writing is oddly precise and fully developed as he describes his confusion: "In my present condition (February 1988, just seven months since diagnosis) there are times when I feel normal. At other times I cannot follow what is going on around me; as the conversation whips too fast from person to person and before I have processed one comment, the thread has moved to another person or another topic, and I am left isolated from the action—alone in a crowd" (pp. 85–86).

Although the writing is still precise, it is in this chapter that Davis's "I" begins to fracture. He has already told us that this chapter was so disjointed that Betty rewrote large parts of it. However, his descriptions themselves point to a separation between who he was and who he is—what Stephen Post calls the "then self" versus the "now self" (Post, 1995b). "In my rational moments," Davis writes, "I am still me" (Davis, 1989, p. 86). The hulking young man who turned down offers from professional football teams to pursue the ministry is contrasted with a man who is "gripped" by paranoia and who is the victim of an "insidious thief who was little by little taking away my most valued possession, my mind" (p. 91). And yet, he directs a message to the friends who knew him, asserting that "I am still the same person . . . I know that one of these days I will not be in here anymore, but for now, maybe for another year or two, I am still home in here" (p. 100). Davis addresses this contradiction head on. "For some reason," he writes, "some segments of society have a hard time dealing with a person who is just partly here." This is clear in Davis's complaint that people expect that if a person cannot work, he or she must be "bedfast, or at least drooling on yourself" (p. 101).

Betty provides the epilogue to Davis's story, and her descriptions of her emotional pain are much more vivid than Davis's are. Perhaps she, as caregiver rather than sufferer, felt less of a need to cleanse her own writing, less under scrutiny. Or perhaps her anguish stems from witnessing the last phases of the disease that Davis is unable to share with us himself. She writes: "Sometimes in weakness and despair I want to give voice to that primal scream starting way down in the hidden recesses of the lungs—down where the ever-present knot that lives in my stomach resides—let it whirl through that vortex that's sucking my life and being into the black hole of never-ending pain, emptiness, and loneliness—just give it voice as it rises and explodes through the top of my head—Noooooooooo! No, God, no!" (pp. 139–140).

4. Journal versus journey

The title of Cary Smith Henderson's (1998) *Partial View: An Alzheimer's Journal* already suggests that the narrative form will be radically different from autobiographies of people with Alzheimer's that came before it. A "journal" carries no expectation of cohesiveness, no desire for a consistent through-line. And Henderson's journal is in fact more free form in style than McGowin's or Davis's autobiographies, containing a loose collection of his thoughts that he dictated into a tape recorder over the period of a year.

Unlike McGowin and Davis, Henderson does not rely heavily on memory to define who he was and, simultaneously, who he is. His narrative voice lives in the present moment, rather than describing the disease with the distance for reflection that more traditional narratives provide. A foreword by a professor of religious studies and an introduction by Henderson's wife Ruth provide the background for Henderson's journal entries. Written after Cary was placed in a nursing home, Ruth's introduction tells the story of his diagnosis, his forced retirement from his career as a professor of history, and of their daughter Jackie's efforts to encourage Cary to write a book on his experience with Alzheimer's. The "self" that *Partial View* creates is clearly and openly a communal effort.

Cary's journal entries are arranged in loose groupings around a variety of topics. He expresses longings for his former life, dread of stairs, passion for music and history, fondness for his little dog, hunger for knowledge, bouts of loneliness and confusion, and empathy for his caregivers. His tone ranges from steadfast seriousness to light-heartedness at the irony of his circumstances—a historian with no memory. "A sense of humor," Henderson writes, "is probably the most important valuable thing you can have when you have Alzheimer's" (Henderson, 1998, p. 14). He demonstrates his gentle humor throughout the journal, usually through word play or explaining how the disease can undermine even the best intentions: "Today I was just really ready to burst out and do something interesting and fulfilling and all other sorts of things like that, and then I learned that I couldn't find my glasses" (p. 42).

Like McGowin and Davis, Henderson sees writing as a way he can help other people with the disease, a way he can make use—and therefore some sense—out of what seems a useless, senseless disease. "I'm taking it as one of my duties," he writes, "to sort of get people with Alzheimer's knowledgeable about what they can expect and what they can do, and of course, what they can't do" (p. 4). Henderson is adamant that people with Alzheimer's are *people* and that they should demand to be treated as such: "I would love to see some people with Alzheimer's not trying to stay in the shadows all the time but to say, damn it, we're people too. And we want to be talked to and respected as if we were honest to God real people" (p. 7).

Henderson also tries to articulate the "in between" status of the "person" with Alzheimer's. "I've been thinking about myself," he writes. "Some time back, we used to be, I hesitate to say the word, 'human beings" . . . I must say this really is, it's living, it's living halfway" (p. 35). "One thing is for sure," he continues. "You can never be, you will never be what you once were. And that's hard to swallow" (p. 35). He is no longer who he was. He is living, but halfway. He used to be a human being. He used to be alive. What is he now? He offers a solution in the book's dedication, from which the title was taken: "The best thing to do about this is just not worry about it. Be happy with the partial view or whatever else is partial, everything is partial."

Unlike McGowin's and Davis's autobiographies in which the narrative form contradicts the experience of the disease, Henderson's nonlinear journal entries both demonstrate and explain the time-quandary that people with Alzheimer’s experience. Four separate entries midway through the journal address time. The repetition underscores his point:

> No two days and no two moments are the same. You can’t build on experience. You can maybe guess what’s going to happen a little while from now—minutes from now, hours from now—we don’t know what to expect. (p. 47)
>
> The scariest thing is, I guess, the fact that I have no sense of time. I have not the slightest idea—my brain doesn’t—what’s ten hours away or what’s two hours away. (p. 47)
>
> And if I think that somebody’s been, that my wife had been gone a while, I get very antsy. And it may be just a short time that she’s been away—it feels like forever. (p. 47)
>
> I feel like it’s time long before anybody else feels like it’s time. It’s just some kind of time warp. (p. 47)

The journal itself echoes Henderson’s “time warp;” in general, it gives no sense of beginning, middle, or end to its structure. Only one of the last entries hints at an ending: “As I ramble around, there are some things that probably ought to be said that I’m sure I haven’t said. But my philosophizing for this day is about finished. I can’t imagine there’s enough tape in there for any more. And what’s more, I think I’ve said all that I can say” (p. 93).

Similarly, the journal form enables Henderson to describe and demonstrate the obsessive paranoia with which so many people with Alzheimer’ are burdened. Several journal entries were made on a day that his wife was sick and his daughter was asleep, leaving Henderson “to my own lights, and . . . uneasy” (p. 31). He can’t remember if the dog has been fed, and he becomes so agitated that he tries to tear open the can: “This was a real, a first-rate panic. I opened up the can with a—let’s see, what did I use for that—uh, well, whatever came at the moment . . . But after tearing up the can, and tearing up a can is a real experience . . . Right now, the doggie seems to be in fairly good shape—I am not sure I am” (p. 31).

Henderson defines himself as a philosopher, an onlooker of life (p. 74). He sees his usefulness as a person in his writing and his volunteering in the medical study at Duke: “And when I get to Durham and I have something I like to do, I’m kind of on a high. It’s something I can do that not everybody can do, and it makes me feel very good about this. It makes me feel like I’m not going to rot in my old age, helpless and stupid” (p. 63). While he makes passing mention of the fact that he taught history, his journal entries are almost completely focused on his present thoughts. And in that present, Henderson is a man “full of feelings”; of love for his family, his dog, his music, the birds and fall leaves; of fears of his own uselessness, of nursing homes, of stairs; and his embarrassment over his inability to give directions in a neighborhood he’s lived in for 20 years. His past, as supplied by Ruth; his relationship to the world of Alzheimer’s, as elucidated by Lonnie Kliever; and his present, as relayed in the journal entries he recorded and his daughter edited, create a self for Cary Henderson better described as full to brimming, rather than partial.

5. Remarkable tales

All three of these texts are remarkable for several reasons, the first of which is that they exist at all. When Alzheimer's strikes, it brings with it enormous financial, emotional, and spiritual challenges. A family's savings are often depleted to pay for care (either a family member who must stay home from work or a paid caregiver) and medical expenses. Confusion and the loss of the ability to communicate make it difficult to perform day to day tasks, let alone tape record or physically write down one's thoughts.

However, these texts are also remarkable for what they teach us about the values and definitions of the self. All three texts suggest that the cultural value of the self is deeply connected to one's usefulness to society. One of McGowin's biggest challenges is admitting that she can no longer work. She fills this hole in her life with writing, in the hopes that her work might one day be useful to others. She takes great pride in the fact that the support group she helped found went on to help others. Similarly, Davis writes to help guide the Christians whom he can no longer minister. Henderson joins a medical experiment in the hopes that his disease might expand medical understanding of Alzheimer's and maybe even one day lead to a cure. He goes through what sometimes seems a humiliating process of tape recording his thoughts to share his experiences with fellow travelers.

Several scholars provide a base of analysis of the self in Alzheimer's disease and dementia that can be helpful here. The late Tom Kitwood's invaluable and substantial body of work, including his 1997 *Dementia Reconsidered*, has consistently pushed for the recognition and treatment of people with cognitive disabilities as whole beings, as selves struggling with cognitive impairment. For Kitwood, personhood has become increasingly measured by autonomy and rationality, categories in which people with Alzheimer's certainly fail to rank very high—in which they even risk failing to register personhood at all. Stephen Post agrees. For Post, autonomy and rationality are clearly legitimized and demonstrated by one's control of memory. And those who reveal memory lapses fall from the category of whole people. Post (1995a) writes: "full self-identity, made possible by an intact memory that connects past and present, should not be overvalued lest those who are disconnected from their pasts by forgetfulness be excluded from the protective canopy of 'do not harm'" (p. 3).

For someone to reveal the stigma of Alzheimer's—forgetfulness, confusion, or broken language—is to risk losing one's status as a whole person (Goffman, 1963). The narrative structure of McGowin's and Davis's autobiographies allows them to share their experiences with Alzheimer's without revealing the stigma of the disease. They talk *about* symptoms, but do not perform them in the writing itself. There are only hints of paranoia in McGowin's account of her high school reunion. Davis openly acknowledges that his wife excised the paranoid passages from his writing. Both are able to maintain a narrative "I" that is assumed to be a whole person, with whom the reader can empathize. Henderson opens himself to more risk by not only describing, but also demonstrating his loss of time, his paranoia, and his difficulty with language.

Hava Golander and Aviad Raz (1996) separate identity into two kinds, offering a distinction that is also useful here. They distinguish "personal" identity, one's awareness of one's self, from "social" identity, the way you are perceived by and interact with those around you. I see personal and social identity as two ends of a continuum. Both are cultural constructs. Our individual sense of who we are, our personal identity, is certainly shaped by culture and our interactions with others. Social identity is more akin to the ways social institutions categorize and sort us. If personal identity is a site of self-reflection in which agency is enacted, social identity tends to be a site where we are acted upon by others. The "whole" self is created by and experienced on both ends of the continuum simultaneously.

While people with Alzheimer's certainly retain a sense of personal identity, their avenues for self-expression are commonly broken. The social identity of people with Alzheimer's, on the other hand, can still be intact or even improved upon. Among people with Alzheimer's disease, McGowin, Davis, and Henderson are exceptional in their ability to relay their personal identities. All three acknowledge, however, that as the disease progresses, they will become less able to define themselves as they once did.

However, in McGowin, Davis, and Henderson's narratives, the crisis of personal identity is only one aspect of the self. The books themselves are quite striking evidence that the social identity of the narrators with Alzheimer's is not only intact, but remarkably strong. Introductions and forewords by family members, doctors, and professors establish the authors' relationships to their communities. Coauthored chapters and assistance with grammar, spelling, editing, and transcribing point not to the weakness of the authors' selfhood, but to the strength of their social identity.

These autobiographies are remarkable for illustrating that there are more ways to express the self than simply through parading one's control of memory. These narrators empathize with those around them, contemplate their fate, express longings and fears, and are, as Henderson (1998) says, "full of feelings" (p. 56). By expressing selfhood in alternative ways, these texts show us how symbiotic memory and identity have become in Western thought. Perhaps expanding our notion of memory can help dislodge us from this rock of individuality upon which we have run aground. Like identity, which is always both personal and social, memory can never be a solely individual act. Memories are formed within culture and triggered through culture (Halbwachs, 1992). Memory, therefore, can be used to affirm and define the self, but always in relation to others. This is the hubris that Alzheimer's narratives expose: we cling to the mistaken notion that personal memory alone constitutes selfhood.

I agree with Augustine in the quotation that opens this essay. Without memory, I cannot, literally, call myself, myself. However, the desire to do so betrays a mistaken notion of self-control, a mistaken notion of memory. Both of these fallacies set up Alzheimer's, related dementia, and late life in general, as a potentially horrifying fall into dependency from a concept of individual autonomy and independence that does not exist. The self is more than memory. It is forged on a continuum of memory and creativity that exists in a social context. Therefore, the person suffering memory loss might suffer the gradual depletion of his or her personal control over identity, but not a total loss of self. Davis's plea to his friends to remember him in a certain way alludes to this. He will be as he is remembered, as people interact with him.

For now, Davis, McGowin, and Henderson have what James Olney (1999) calls a contested, cautious, and uncertain "I." They are not alone. This "I," better understood perhaps as the "Not I," Olney believes (and I agree) to be *the* defining pronoun of the twentieth century (p. 261). It is the “Not I,” a self in transition, that weaves through much of twentieth-century literature, of Samuel Beckett and Gertrude Stein, of Holocaust memoirs, of memoirs tracing the civil rights movement, and of literary theory during the 1980s and 1990s. All of these (and there are many more examples) capture the unfolding, but never fully materializing self under strain of combat, abuse, oppression, and the general passing of time.

Until the publication of Henderson’s *Partial View*, biographies and autobiographies about people with Alzheimer’s have tended to be fairly traditional in form. They fight to gather up the fragments of self into a recognizable whole as part of the battle against the disease. The autobiographies that tell their stories in chronological form contradict the disease itself and undermine the full potential of expressing the uniqueness of the “I” of someone with Alzheimer’s. Instead, they create a reflective “I” who looks back on the course of the disease from a place where cohesive sentences are, in the real life of the disease, impossible. The authors ultimately cannot maintain the mask. They must be helped by machines or coauthors that might or might not be given credit. The autobiography in this form serves as a tribute to the author (a self-cleansed of the disease) and demonstrates (although usually cloaked) the strength of social identity. Authors borrow the myth of the fully independent “I” (personal identity) to give strength and courage to those facing the disease.

McGowin’s and Davis’s autobiographies might also use this more traditional autobiographical form because, at the time these texts emerged, knowledge of the disease was fairly limited. A standard autobiographical form was the logical choice to reach the widest audience and to frighten them the least (by describing, rather than embodying the disease). *Partial View*, published in 1998, appears in a radically different social context. Awareness of the disease has risen dramatically as strong national organizations lobby for research money and provide information and support networks.

It is also possible that textual autobiographies are simply limited in the kind of disease experiences they can portray. New autobiographies on the worldwide web by people with Alzheimer’s disease will expand on Henderson’s model and potentially offer us an even greater glimpse into the embodied experience of the disease. Videos, multimedia installations, nonlinear CD ROMS, and even plays are already appearing. And with them, we will stand to gain a deeper understanding of the disease and our shifting values of selfhood.

References

Couser, T. G. (1997). *Recovering bodies: illness, disability, and life writing*. Madison, WI: University of Wisconsin Press.

Davis, R. (1989). *My journey into Alzheimer’s disease*. Wheaton, IL: Tyndale House.

Frank, A. (1995). *The wounded storyteller*. Chicago, IL: University of Chicago Press.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

Golander, H., & Raz, A. (1996). The mask of dementia: images of ‘demented residents’ in a nursing ward. *Ageing and Society*, *16*, 269–285.

Halbwachs, M. (1992). *On collective memory*. Chicago, IL: University of Chicago Press, L. A. Coser, Trans.

Henderson, C. S. (1998). *Partial view: an Alzheimer’s journal*. Dallas, TX: Southern Methodist University Press.

Holstein, J., & Gubrium, J. (2000). *The self we live by: narrative identity in a postmodern world*. New York: Oxford University Press.

Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Buckingham, England: Open University Press.

McGowin, D. F. (1993). *Living in the labyrinth*. New York: Delacorte Press.

Olney, J. (1999). *Memory and narrative*. Chicago, IL: University of Chicago Press.

Post, S. (1995a). *The moral challenge of Alzheimer's disease*. Baltimore, MD: Johns Hopkins University Press.

Post, S. (1995b). Alzheimer's disease and the 'then' self. *Kennedy Institute of Ethics Journal*, *5*(4), 307–321.

Anne Davis Basting, PhD, is an independent scholar and artist in Brooklyn, NY, where she directs the TimeSlips Project (www.timeslips.org). Basting has written extensively on issues of aging and representation, including her 1998 book, *The Stages of Age: Performing Age in Contemporary American Culture*.