

Authorship, Alzheimer's and the illness memoir

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Christoph Ribbat

Authorship, Alzheimer's, and the Illness Memoir

1. Cornerstones

The numbers alone are staggering. In 2003 around 4.5 million Americans suffered from Alzheimer's disease – twice as many as in 1980. The figure is expected to rise to 11.3-16 million in 2050.¹ With an aging, more long-lived population and no cure in sight, dementia may soon become, in the words of science journalist David Shenk, “one of the defining characteristics of civilization, one of the cornerstones of the human experience.”²

In response to such warnings literary critics may first express their indifference for statistics. Then they might challenge the hyperbole and point out that neither “cornerstones of the human experience” nor civilization’s “defining characteristics” emerge out of thin air.³ In a study called *No Aging in India* anthropologist Lawrence Cohen argues that non-Western ideas of aging, memory, and intergenerational togetherness expose such concepts as Alzheimer's disease as highly contingent cultural constructions.⁴ The medical soci-

1 American Alzheimer's Association: “Statistics of Alzheimer's Disease”, online, www.alz.org/AboutAD/Statistics.asp, 29 August 2006. See also Carl Turkington and James E. Galvin, *The Encyclopedia of Alzheimer's Disease*, New York, Facts on File, 2003, p. 14. I would like to thank Franziska Gyax for some excellent suggestions that helped give shape to this essay.

2 David Shenk, *The Forgetting: Alzheimer's: Portrait of an Epidemic*, New York, Anchor, 2003, p. 5.

3 Shenk himself, it should be added, emphasizes the problematic role of modern science in reducing Alzheimer's ambivalent dimensions as a human condition to a “plain horror” (p. 252).

4 Lawrence Cohen, *No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things*, Berkeley, University of California Press, 1998.

ologist Renée L. Beard reads the dementia discourse as the expression of an “antiaging mentality” ultimately aiming to ‘cure’ aging itself.⁵ In a Foucauldian analysis the Alzheimer’s era appears as the latest stage in the history of the clinical gaze. Brain scans detect and categorize the demented and the soon-to-be demented. The “invention” of Alzheimer’s disease may rank as yet another example of modernity turning “wonder” into “error” (Thomson). In the space of just a few decades the strangeness of the old has been transformed into a medical category of the abnormal.⁶

And yet, though all of these arguments sound convincing in critical theory, none of the above seems to matter in the world of Alzheimer’s. To patients, caretakers, and scientists finding the cure is what counts.

Summarized this briefly the Alzheimer’s discourse highlights some of the most cemented controversies between ‘hard science’ and the postmodern humanities. It’s hard to find a middle ground between these two sets of obsessions: the frantic race for success on the one hand and the constant questioning of ‘seemingly natural’ concepts on the other. A pragmatic approach may have to develop a different take on constructedness vs. factuality. Like all diseases, Alzheimer’s was created by texts. But the condition and its attendant discourse may be especially close to literary and journalistic expression simply because dementia attacks the very fundamentals of symbolic communication: memory and language. Hence Alzheimer’s has stimulated an extraordinary number of narratives in recent years. Literary and journalistic texts translate the deterioration of the brain to the larger culture, making the disease ‘real’ simply by establishing its representations in

5 Renée L. Beard, “In Their Voices: Identity Preservation and Experiences of Alzheimer’s Disease”, *Journal of Aging Studies* 18, 2004, p. 416 (pp. 415–428).

6 Rosemarie Garland Thomson, “Introduction: From Wonder to Error – A Genealogy of Freak Discourse in Modernity.” *Freakery: Cultural Spectacles of the Extraordinary Body*, ed. Rosemarie Garland Thomson, New York, New York University Press, 1996, 3 (1–19). For a critical reading of postmodernist theory in the context of disability studies see Lennard J. Davis, *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions*, New York, New York University Press, 2002.

the heart of American everyday life. Most of these works classify as nonfictional texts – memoirs, essays, and autobiography – representing the disease nonetheless in their own specific generic frameworks.⁷ Exploring these narratives, this essay argues, may be the best first step for literary critics to develop a position from which to read the new “Alzheimer’s culture”: the textual reality of the disease.

And there are more than just demographic reasons for the surge in Alzheimer’s writing. The memoir as such became “the master genre” of the American 1990s and still hasn’t lost its appeal. The key theme of these true stories was suffering: the detailed rendering of oppression, violence, and illness. Victims turned into literary heroes. The “AIDS sufferer, the assaulted girl child, the ordinary person who survived” (Steiner) became the typical speakers and protagonists of the most popular memoirs, texts that became integral parts of the post-modern culture of confessionalism just as much as the late-20th century daytime television talk show.⁸ The 1970s fusion of the personal and the political survived in the memoir as in no other literary genre. Janet Ellerby, a historian of the women’s memoir, reads these narratives as “threshold[s] from which we step into the dynamic, complex experience of real women’s lives.” Autobiographical works ask their readers to examine their “ethical agenda,” Ellerby states, and assumes with some optimism that “we can all become more connected” via the memoir’s honesty, specificity and the interchange triggered by reading and writing autobiographical texts.⁹

Not all observers have shown this sort of enthusiasm for the genre. The conservative scholar Gertrude Himmelfarb has

7 See for a brief bibliographical essay on Alzheimer’s-related autobiographical texts: Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*, West Lafayette, IN, Purdue University Press, 1999, 217–218.

8 Wendy Steiner, “Postmodern Fictions, 1970-1990”, *The Cambridge History of American Literature, Vol. 7: Prose Writing 1940–1990*, ed. Sacvan Bercovitch, Cambridge, Cambridge University Press, 1999, pp. 535sq. (pp. 425–538.)

9 Janet Mason Ellerby, *Intimate Reading: The Contemporary Women’s Memoir*, Syracuse, NY, Syracuse University Press, 2001, p. xx–xxi.

described contemporary autobiographical writing as narcissistic, solipsistic, even shameless.¹⁰ Peter Kramer notes how “[b]ookstore shelves groan with memoirs of heart disease and asthma. No mental disorder, from alcoholism and autism to schizophrenia, is without its confessions.” Illness narratives, a study of the genre emphasizes, are frequently seen as subliterary, extraliterary, mere symptoms of a society’s obsession with victimhood.¹¹

Discounting the reading and writing of memoirs as a mere populist craze, however, seems comparatively difficult in light of the tight and complex linkages between the autobiographical text, illness, and cultural theory.¹² Anne Hunsaker Hawkins calls “pathography” the “adventure story” of our time, a “rich source” for the literary critic, to be analyzed as parables both of collapse and the process of achieving new balance.¹³ Beyond the text itself numerous relevant political and ethical questions appear. “[T]elling stories about illness,” Arthur Frank proclaims, “is to give voice to the body, so that the changed body can become once again familiar.”¹⁴ Frank emphasizes the “moral genius” of illness storytelling and the goal to “change one’s own life by affecting the lives of others.”¹⁵

There is not nearly enough space here to properly map the field of Alzheimer’s writing against the background of these debates on the memoir’s literary value. This essay casts spotlights on two individual works and hopes to sidestep scholastic discussions of literariness by selecting nonfiction texts by two widely recognized American writers: Jonathan Franzen’s essay “My Father’s Brain” (2001) and fellow novelist

10 Gertrude Himmelfarb, “A Man’s Own Household His Enemies”, *Commentary*, 108, 1, 1999, p. 34.

11 Qtd in Thomas Couser, *Recovering*, *ibid.*, p. 7.

12 Franziska Gyax, “Erzählen von Krankheit als Autobiographie und Theorie”, *Narration und Geschlecht: Texte – Medien – Episteme*, hg. Sigrid Nieberle und Elisabeth Strowick, Köln, Böhlau, 2006, p. 410 (pp. 409–422).

13 Hawkins, *Reconstructing*, *ibid.*, pp. 1–3.

14 Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, Chicago, University of Chicago Press, 1995, p. 2.

15 Frank, *Wounded*, *ibid.*, p. 18.

Sue Miller's memoir *The Story of My Father* (2003). The most provoking questions in these works relate to the issue of authorship. What is the role of the author in mediating between the medical and the literary? How to read autopathography (texts *by* the ill) – how to study illness memoirs (texts *about* the ill)? How do authors reflect their own work, position, and identity when confronted with Alzheimer's Disease? What alternative concepts of authorship exist in Alzheimer's culture? Some of these questions will lead this essay beyond Franzen's and Miller's works and toward a discussion of patients' self-expression. But the writers' memoirs will provide a framework here, relied on as clear positions in a burgeoning discourse.

2. Facing Alzheimer's: The Mind and the Brain

Sue Miller's memoir *The Story of my Father* carefully chronicles the disease and death of her father in the late 1980s. Fathoming the depths of Alzheimer's disease clearly ranks as one of the text's goals, just as the investigation of the personal relations that are transformed by the father's disease but also shape its impact. Another ambition can be detected in Miller's memoir, however: the author's desire to learn about the neurobiological realities of the disease and to present them in a useable, readable narrative.

In a central chapter of her memoir Miller describes the typical signs of Alzheimer's disease: neurofibrillary tangles (changed neuronal elements of the brain) and the senile plaques (deposits of abnormal proteins). Her prose makes matters simple. "When you look at microscopic pictures of those plaques and tangles," she explains, "there's a Jackson Pollock quality to their appearance." She compares the tangles to "blobs of paint thrown hard at the canvas."¹⁶ Moving on to the "curly fibers" in the brain (decayed nerve endings), the imagery is even closer to home. Miller compares what she sees on brain scans to "a linoleum on the kitchen floor" in her

16 Sue Miller, *The Story of My Father: A Memoir*, New York, Random House, 2003, p. 70. Subsequent references appear in the text.

childhood home, a surface that, “though more riotous in color than any of the available stains used to reveal these structures, bore some resemblance in its splattered pattern to this picture of disease” (71).

The extraordinary combination of brain scan images, Pollock’s paintings, and the linoleum on the kitchen floor may point to central themes and problems not only in literary representations of Alzheimer’s, but in the genre of illness narrative as such. Thomas Couser identifies the dynamic relationship between the medical discourse on the one hand and the language of subjectivity on the other as the driving force behind pathography. If the images of the father’s brain, of plaques and tangles, were perceived as elements of a larger, depersonalizing, medical process, the daughter’s narrative could serve as a “way of resisting or reversing” the “expropriation of experience by an alien and alienating discourse”.¹⁷ According to Couser literary accounts of illness involve a “reclaiming” of the body.¹⁸ The familiar paintings and the domestic space of an author’s childhood could then function as signposts, pointing the text back to the intimate story and away from the clinic’s apparatus and language.

Miller’s memoir, however, does not seem all that interested in a postcolonial turn against the encroaching medical gaze.¹⁹ *The Story of My Father* incorporates the latest findings of the neurosciences, using bits and pieces on nerve cells and neurotransmitters without any particular detachment. More than this, Miller ties the latest brain science to an account of her parents’ relationship. The author cites studies indicating that certain markers of Alzheimer’s are visible early on in life. Her father’s detachedness and emotional unavailability Miller therefore describes not as ‘abiological’ character traits, but as signs and functions of his later dementia – and as significant forces in his marriage. “Perhaps,” Miller speculates about her mother, “it was in part his Alzheimer’s-ness she fell in love

17 G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing*, Madison, University of Wisconsin Press, 1997, p. 29.

18 Couser, *Recovering*, *ibid.*, p. 35.

19 On the relationship between postcolonial thinking and illness narrative see Frank, *Wounded*, *ibid.*, p. 13.

with" (72). While noting how "funny" the thought seems, Miller describes her "mother as a chemical force [...] laying siege to my father's brain." The climax of the passage reveals Miller's conviction that chemicals were indeed playing a central role in her parents' lives:

When my mother wailed to my father, "I would like you *just once, just once* to try and remember what it was that attracted you to me in the first place!" maybe she was really insisting that he lay down some new neural pathways, just for her. And if he did it, and did often enough, maybe that added density helped him resist Alzheimer's Disease a little longer than he might have otherwise (73).

Finally, some readers may say, a literary text seems truly informed by neuroscience. Miller frames the rocky romance between her parents not in the 'soft' terms of emotions and identity constructions, but in the 'hard' language of the chemical. The passage hints at a marriage of two brains, not minds (though the mother's brain, the healthy one, receives comparatively little attention). In his early work *The Man Who Mistook His Wife for a Hat* Oliver Sacks proclaims that "we must deepen a case history to a narrative or tale," arguing for a crossing of the "gulf" between the physical and the psychical, for an exploration of "studies and stories pertaining simultaneously and inseparably to both."²⁰ Miller's sketch of her parents' relationship could be understood as the logical continuation of Sacks' ideas. Were neuroscience fully accepted by writers, the gap between case study and story would indeed close. All stories would turn into case studies, all relationships into long-term chemical experiments.

The reading may be somewhat overstated. Clearly, however, neither Sue Miller nor Jonathan Franzen set out to deconstruct the medical discourse in the ways suggested by the leading scholars of illness writing. Franzen's essay praises the idea as "lovely and postmodern" that the "human brain is

20 Oliver Sacks, *The Man Who Mistook His Wife for a Hat*, [1985], London, Picador, 1995. p. x. For an extended discussion of Sacks' works in the context of narrative ethics see G. Thomas Couser, *Vulnerable Subjects: Ethics and Life Writing*, Ithaca, Cornell University Press, 2004, pp. 74–122.

a web of a hundred billion neurons, [...] with trillions of axons and dendrites exchanging quadrillions of messages by way of at least fifty different chemical transmitters.”²¹ His essay on the father’s death also serves as a memoir of the author’s gradual transformation from Foucauldian cultural criticism to an acceptance of neuroscientific language and observations. Once, Franzen ‘confesses’, the term Alzheimer’s “seemed to me another instance of the medicalization of human experience, the latest entry in the ever-expanding nomenclature of victimhood” (19). Not anymore. Now the brain seems more interesting than the mind, though the tension between culture and nature still informs the essay. Franzen identifies “a blind spot” in his thinking, a spot “across which I [...] interpolate stories that emphasize the more soul-like aspects of the self” (19). Franzen, though aware of the chemical processes, “persisted in seeing a whole” out of love for his father and holds on to a myth of selfhood in spite of the Alzheimer’s narrative of deterioration: “I’ll go to my own grave,” the author proclaims, “insisting that my father was determined to die and to die, as best he could, on his own terms” (36).

3. Alzheimer’s Authors: Memoirs, Autopathography, Workshops

Both *The Story of My Father* and “My Father’s Brain” tell two interlinked stories: one dealing with the father’s disease, one chronicling a healthy writer’s explorations of Alzheimer’s as both personal and scientific issue. Naturally the author plays a problematic role in these representative texts of contemporary life writing. In Thomas Couser’s terms Franzen’s and Miller’s works would classify as “illness memoirs”, a form provoking a much different set of questions than the genre “autopathography.” Mortality, identity, the consciousness of the self and its contingency: all these are distinct features of the autobio-

21 Jonathan Franzen, “My Father’s Brain” [2001], *How To Be Alone: Essays*, New York, Farrar, 2002, p. 10 (pp. 7–38). Subsequent references appear in the text.

graphical account, Couser states. They may also serve as central themes in writings by the healthy family member or friend. But the memoir, quite obviously, is unable to “render the subjective experience of illness.” Instead it foregrounds the conditions and outcomes of the disease.²² No matter how close the relationship between author and patient, the memoir written by daughter, son, or partner lacks the autopathography's postcolonial energy. It does not “write back” against medical discourse. Struggling with the clinic may figure as a theme in the relative's memoir – yet the text is still produced by a healthy voice speaking for and about the silent patient.

In the case of British author John Bayley's memoir *Iris: An Elegy* critics have foregrounded the problem of authorship from very different angles. To John Wiltshire the combination of John Bayley's voice and Iris Murdoch's silence do not constitute a problem. Instead he regards Bayley's memoir of his wife, the novelist and philosopher, as a study in “intersubjectivity,” a text transcending the generic categories of illness narratives. *Iris: An Elegy* demonstrates, in Wiltshire's reading, just how much the supposedly healthy speaker and caretaker depends on the demented patient.²³

Gertrude Himmelfarb's view of Bayley's narrative is diametrically opposed to Wiltshire's reading. To Himmelfarb being “eviscerated by their nearest and not-so-dearest” seems the fate of public figures in contemporary culture. *Elegy for Iris* is treated in her essay as an “egregious example of this invasion of privacy.” The critic underscores the importance of privacy in Murdoch's life and work and perceives cynicism in each and every tell-all memoir, by however loving a partner. Now, Himmelfarb argues, no reader will remember Murdoch as “Dame of the British Empire,” nor as the author of twenty-six novels as well as numerous philosophical works, but as “the pathetic soul who resisted having her socks removed when she was coaxed into the water or who spent the morning watching Teletubbies on television.”²⁴

22 Couser, *Recovering*, *ibid.*, p. 6.

23 John Wiltshire, “Biography, Pathography, and the Recovery of Meaning”, *The Cambridge Quarterly* 39, 4, 2000, pp. 421sq. (pp. 409–22).

24 Himmelfarb, “Man's”, *ibid.*, p. 35.

Such are the ethical problems of the memoir. They rank as issues of little significance in autopathography when the patient reclaims his or her story from medical discourse, symbolically asserting autonomy. Then again the Alzheimer's patient, memory and language skills under attack, does not seem to be given much of a chance to perform these literary acts. How is it possible in an Alzheimer's autopathography to use the narrative as an "act of protest", a "critique of medicine," an act of rescuing the "experience of illness and medicalisation from the narrower definitions of the clinic"?²⁵ Autobiographical illness writing intends to bridge the gaps and the "sense of discontinuity" that the illness once created in the author's self.²⁶ How is that possible if the very faculties needed to compose a story are rapidly disappearing?

In spite of the challenges some autobiographical works by Alzheimer's patients exist. One of them, Thomas DeBaggio's *Losing My Mind: An Intimate Look at Life with Alzheimer's*, challenges memory' deterioration by weaving together a set of narrative strands: childhood memories, reflections on his condition, meditations on personal relationships. But DeBaggio's text never becomes fully independent of the medical discourse. The text frequently cites long passages from scientific writings, so frequently that its narrative eventually resembles a collage of diary entries and excerpts more than a unified story countering the disease. DeBaggio's text seems document more than tale. The very existence of the book – autobiography by a man attacked – appears as more significant than anything developed on its pages.²⁷ Autopathography's key figure is the self, the self recovering via story. But DeBaggio's book, quite naturally so, may not be a product of a self at all. It's a collaborative project by several authors (family members, friends, science writers) with the author serving as a figurehead providing a sense of symbolic coherence to a disparate text. To the reader of classic American autobiography

25 Wiltshire, "Biography", *ibid.*, p. 412.

26 Shlomith Rimmon-Kenan, "The Story of 'I': Illness and Narrative Identity", *Narrative* 10, 1, 2002, p. 11 (pp. 9–27).

27 Thomas DeBaggio, *Losing My Mind: An Intimate Look at Life with Alzheimer's*, New York, Free Press, 2002.

this may seem questionable. Shlomith Rimmon-Kenan argues, however, that in illness writing the “disintegration and fragmentation” of the text not only exposes the “vulnerability” of the ill subject, but also suggests “the limitations, perhaps even the *hubris*, of the better-structured narratives.”²⁸

A broader reading informed by postmodern theories of authorship and intertextuality would argue that only gradual differences exist between sane authors, seemingly autonomous, and the way in which DeBaggio's narrative is drifting toward intertextual collage. In their own way the disease of the author described in *Losing My Mind* and the death of the author envisioned in late 20th century theory both address the impersonalising tradition in modernist writing. With a significant difference: in poststructuralism this is a deliberate negotiation, whereas DeBaggio's life writing needs to be read against the grain in order to make connections to current literary theory. Even more than this – and much more importantly: DeBaggio unequivocally mourns the loss of self, autonomy, individuality. *Losing My Mind* is an expression of the deep yearning to hold on to all the concepts called into question by poststructuralism. There is no “unease about the subject” in DeBaggio's work, just desperate attempts to regain subjectivity.²⁹

It can only be speculated here how representatives of the “third culture” (Steven Pinker comes to mind) would respond to this paradoxical situation. Postmodern theorists set out to deconstruct the seemingly oppressive myths of the autonomous self – and Alzheimer's patients care about nothing but autonomy. The setup seems to lend itself perfectly to anti-theoretical satire.

But postmodern theory and Alzheimer's practice are not as distant from each other as they may appear. The scholar Anne Davis Basting, for instance, develops practical forms of self-expression for Alzheimer's patients that are fundamentally different from autopathographical writing shaped by the

28 Rimmon-Kenan, “Story”, *ibid.*, p. 22.

29 Séan Burke, “Introduction: Reconstructing the Author”, *Authorship: From Plato to the Postmodern: A Reader*, ed. Séan Burke, Edinburgh, Edinburgh University Press, 1995, pp. xxiv (xv–xxx).

individual author, the coherent narrative, the identifiable voice. Basting's *Time Slips* storytelling projects, collaborative workshops for demented patients, are based on the notion that the "consistent 'I'" of "linear autobiographies" will always be forced to play down or "mask" the patient/author's dependence on caregivers/co-authors. The workshops encourage "creative expression not reliant on memory," Basting points out, stressing the "relational quality of the self" and "the social identity of people with dementia by giving them a role to play in their institutional settings."³⁰ Specifically, Alzheimer's patients produce collaboratively authored stories by individually contributing their responses to photographs shown to them in a storytelling session. The stories are not only recorded by staff facilitators. The guides also stimulate the patients regularly – by their questions, by calling for responses, and by "fold[ing] all the answers into the open narrative."³¹

The *Time Slips* project neither foregrounds memory nor the self as protagonist/author, nor memory. "Together our storytelling groups were going to make up *new* stories," Basting proclaims.³² Patients provide fragmented observations to a narrative collage resembling the poetry of high modernism. Coherence, unity, *the* life story are features the collaborative projects eschews (unlike DeBaggio's *Losing My Mind*, a text still announcing an overarching life narrative). What is produced are such text passages as "Anna is sitting on a pail. / Anna is friendly with everybody. / Anna's friend is an elephant. / Leave Anna alone!" that suddenly turn into seemingly metaliterary passages ("It's too much of a story to be a story / Writing has its limits. / It can't be blown up like a balloon.")³³ There is no sense of linearity and no attempt is made to create it.

30 Anne Davis Basting, "Dementia and the Performance of the Self", *Bodies in Commotion: Disability & Performance*, ed. Carrie Sandahl and Philip Auslander, Ann Arbor, University of Michigan Press, 2005, p. 204 (pp. 202–213).

31 Basting, "Dementia", *ibid.*, p. 205.

32 Basting, "Dementia", *ibid.*, p. 204sq. See also the website presenting the project, stories, etc: www.timeslips.org.

33 Basting, "Dementia", *ibid.*, p. 207. See appendix for complete text.

Basting emphasizes the therapeutic and social potential of the patient collectives and their production of stories. In her view the openness of the texts and their “poetic qualities” enable families to “connect, at least psychologically, with each other and with the storytellers.” There are no individual authors in *Time Slips*, no names appear to identify voices. The texts are “composites of the voices of all participants, the facilitators and the storytellers.”³⁴ In an earlier essay Basting explicitly questions what she defines as the myth of individual independence in the context of authorship. In her view Alzheimer's narratives expose the “mistaken notion” in Western culture “that personal memory alone constitutes selfhood.” The person losing her memories does not necessarily lose his or her self, Basting argues. The “potentially horrifying fall into dependency from a concept of individual autonomy and independence” may be a mere construct. The self should be seen, she states, as “forged on a continuum of memory and creativity” existing “in a social context.”³⁵

Some issues need to be raised here. Basting describes the *Time Slips* stories, in the language of literary realism, as “rare window[s] into the world of dementia.”³⁶ Yet what can be perceived behind these windows is highly difficult to identify. Are readers encountering actual selves here? Relational selves? Or relational selves guided along by “facilitators”? Are these texts perhaps merely, say, ‘interesting’ products of one of numerous therapeutic projects – innovative, creative, and yet streamlined by so many rules and regulations that they just won't qualify as literary texts or even as individual expression? The story telling circles may function in a similar way as group reminiscence therapy, which, as scientists say, helps

34 Basting, “Dementia”, *ibid.*, p. 20sq.

35 Basting, “Looking Back from Loss: Views of the Self in Alzheimer's Disease”, *Journal of Aging Studies* 17, 2003, p. 97 (pp. 87–99). See also: Paula M. Usita, Ira E. Hyman, and Keith C. Herman, “Narrative Intentions: Listening to Life Stories in Alzheimer's Disease.” *Journal of Aging Studies*, 12,2, 1998, p. 195 (pp. 185–197). For an approach emphasizing the function of the body in Alzheimer's self-expression see Pia C. Kontos, “‘The Painterly Hand’: Embodied Consciousness and Alzheimer's Disease”, *Journal of Aging Studies*, 17, 2003, pp. 151–170.

36 Basting, “Dementia”, *ibid.*, p. 208–9.

fight depression in Alzheimer's patients as life stories enhance caregiving and communication.³⁷ But is there any significant way in which the texts collected by the Time Slips facilitators reach beyond the therapeutic discourse?

How this question is answered depends on one's attitude toward Basting's basic assumptions. The independent self - hallowed by American culture and cherished by authors of autobiographical prose - Basting perceives as a mistaken notion. Following her suggestions would lead to an acceptance of these groups of patients, student helpers, and caregivers as bona fide authors of Alzheimer's literature. For doubtful critics the works by Jonathan Franzen and Sue Miller probably remain the best bet.

4. The Men (and Women) of His Own House

And yet the problem of narrative ethics will always haunt these texts. In both Miller and Franzen the father at times appears transformed by the illness to the point of grotesqueness. Franzen's essay describes the father "listing in his wheelchair like an unstrung marionette, eyes mad and staring, mouth sagging, [...] my mother's face a mask of reasonably well-contained despair" (28). In Miller's account the father is depicted as wearing diapers, his "jackets or ties smeared with shit in the pile of dry cleaning"(141). Taken out of context such passages connect immediately to Gertrude Himmelfarb's polemic comments on the Alzheimer's memoir. As the confessionals unfold they expose to their readers a reticent Princeton church historian (Miller's father James Nichols) and a man named Earl Franzen who, as his son explicitly states, "was an intensely private person" to whom privacy "had the connotation of keeping the shameful content of one's interior life out of public sight." Franzen the younger asks: "Could there have been a worse disease for him than Alzheimer's?" (24) What's the answer here? Perhaps that yes, the one thing worse was to posthumously have his life and his "mad and

37 Usita, Hyman, and Herman, "Narrative", *ibid.*, p. 195.

staring" eyes, his "sagging" (28) mouth described for hundreds of thousands of readers.

There is one important strategy, of course, that will turn the protagonist of the nonfiction narrative into a subject: citing his own voice, his own texts, and thus transforming him into a co-author of the literary work. Franzen's father does appear as an author in this essay. But the letters cited in "My Father's Brain" most importantly serve as documents of his struggle against the illness, as indications of his forgetfulness (One letter may have remained unsent, because, as Franzen speculates, "[p]ossibly my father was ashamed to send a letter that he knew wasn't fully coherent; more likely, given the state of his hippocampal health, he simply forgot" [34]). More central than the father's letters are those written by Franzen's mother – accounts of the father's conditions, his "mistakes", the general confusion. The true author of the essay is frank about the aporia of Alzheimer's self-witnessing. In contrast to Basting Franzen sees autonomy as a precondition to authorship. "This was his disease," Franzen states. "It was also, you could argue, his story. But you have to let me tell it." (11)

Sue Miller's *Story of My Father* handles the two possible authors – the father himself and the writer she is – in quite similar terms. Her memoir portrays a historian, and therefore a professional writer, yet not much attention is paid to the father's actual academic work. Early on Miller cites a homily written and given by her father at her older brother's wedding. This document, too, is not discussed autonomously. It provides a first hint at the father's beginning dementia, when Miller describes how the father struggles while trying to read the speech at her own wedding years later. At the very beginning of *Story of My Father* the role of the author thus shifts from father to daughter, from the ill to the healthy. The homily's insistence on choice – "It is wonderful indeed that we can choose [...] but still more wonderful that we are chosen (8)" – seems highly ironic as Miller's book chronicles precisely the father's ever-growing incapacity to choose. He remains chosen, of course, but chosen also as topic rather than subject.

Reflections on the author's own role receive much more space in *Story of My Father* than in Franzen's short essay. But the notions presented by Miller run along parallel lines. The

author explores memory because the father's memory is destroyed. Miller, like Franzen, closely investigates the functions of family stories in a time when Alzheimer's radically transforms several stories at once. Unlike Franzen, Miller gives a detailed account of her development as an author – and, specifically, as an author of this kind of nonfictional, autobiographical text. Her epilogue chronicles her various attempts to tell the father's story, her struggles with voice, and her own narrative theories. Miller describes what she first saw as her memoir's goals – to struggle with “the disorder and oblivion” marking her father's illness and death, the idea to “snatch him back from the meaninglessness” of Alzheimer's” (161). But the memoir then transformed into another project, the final version of it. Eventually the text began to explore her own struggles as the author “revisit[ed]” her own “childhood fear of abandonment”. The true theme of her memoir, Miller eventually states, “was the course of the disease itself – not because it took my father from me but because it took him from me *again* [...]. [W]hat I was confronting and dealing with as I wrote was that terror, that selfish childish terror.” (171)

And the literary struggle for Miller finally leads to a sort of comfort produced by work itself. By the “making of the story”, she points out in the last lines, it is that “I have been, as the writer that I am, also consoled” (171). *The Story of My Father* turns into the story of a daughter and an author. Like Jonathan Franzen's essay Sue Miller's memoir pays just as much attention to reading and writing as to the transformations wrought by the disease. Instead of questioning the self these texts provide comfort, bolstering the autonomous self instead of exposing it as myth.

One of Miller's sources makes for a surprising parallel to Himmelfarb's attack on the memoir. Miller describes a childhood fear triggered by lines from Matthew envisioning that “a man's foes” shall be the members “of his own household” and how she imagined herself as “that daughter to be discarded” (166) when reading the lines: “he that loveth son or daughter more than me is not worthy of me” (Matthew 10: 36–37). Himmelfarb's diatribe cites the exact Old Testament passage (Micah 7:6) that this text from Matthew refers to: the concept that a man's enemies will be “a man's own household”, the

“men of his own house,” as the King James Bible puts it, in a larger vision of the moral corruption of Israel. In Himmelfarb’s essay the phrase points at the dangers of contemporary American corruption: intimate space seems to cease to matter as sons, daughters, and partners describe their loved one as sick or guilty for a nation of endlessly curious readers. To Miller the enemy of and in the household is not the writer at all. It is the father, her father, abandoning the child – first as a healthy, though reticent man occupied by his academic work, then as a patient lost in the throes of Alzheimer’s disease. The same biblical passage that leads Himmelfarb to challenge the culture of confession triggers Miller’s meditations on the intimate sphere, a space to be opened for her readers without reservations. Miller, like Franzen, relates these and so many other observations to a writer’s self that’s larger than anything else in the text – the self of the independent author making sovereign use of his or her material.

The not so simple question attending these memoirs is whether they take part in a larger social and cultural movement to make the lines between the sane and the demented ever more impermeable, perhaps inadvertently, simply by displaying the power of sane authorship in the very process of depicting dementia. Or, quite in contrast, do these personal memoirs help to erase these lines – by also opening perspectives, sometimes painfully intimate, on the pain and confusion of the ‘sane’? Such questions are directly linked, as Thomas Couser points out, to the field of bioethics. At what point does representation violate the subject’s autonomy? Where does one’s own self-representation infringe on someone else’s privacy? How, Couser asks, should “concern for aesthetics” be related to “concerns for ethics?”³⁸

Of course these issues relate not only to the discourse of illness, but to nonfiction writing in general. (Joan Didion put it most succinctly: “writers are always selling somebody out.”)³⁹ The ‘Age of the Memoir’ seems to take it as a given that life stories written by partners or children form the foun-

38 Couser, *Vulnerable*, *ibid.*, pp. x–xi.

39 Joan Didion, *Slouching Towards Bethlehem* [1969], London, Flamingo, 1993, n. pag.

dation of American culture's negotiations with dementia. The patients themselves, however, may or may not wish to be involved in these rituals of confession. Alzheimer's patient Thomas DeBaggio, for one, closes his work *Losing My Mind* with one simple wish addressed to his partner: "Hug me, Joyce, and then let me sleep."⁴⁰

⁴⁰ DeBaggio, *Losing*, *ibid.*, p. 207.

6. Appendix

The full text of a story produced by a storytelling circle under the auspices of the *Time Slips* project:

Unconsciously Making Things Too Small

(In response to an image of an elephant and a little girl)

This is a story about Anna.
 Anna is friendly with everybody.
 It's medium outside, a medium summertime day.
 Anna's friend is an animal, an elephant, to be specific.
 God knows where they met.
 Together they have a home, but we're not sure where.
 It's their own business what they do.
 There are too many answers – everybody has different answers.
 There's a chicken and a little tree in the background.
 The story is much bigger than the elephant.
 It's so big, you can't go oversimplifying it.
 You cannot put things like that.
 Unconsciously we try to make things too small.
 Every person has a story.
 There's no human being that doesn't have a story.
 But making it mish mosh [*sic*] is bad.
 It's like a bomb.
 Anna is sitting on a pail.
 Anna is friendly with everybody.
 Anna's friend is an elephant.
 Leave Anna alone!
 It's too much of a story to be a story.
 Writing has its limits.
 It can't be blown up like a balloon.
 Anna is listening to the elephant's heartbeat.
 Her hand looks like a chicken's foot.
 Anna and the elephant are waiting for a ride.
 But it's stupid to have a car in the background.
 They are not iron and nails!
 Anna and the elephant are singing a song. We knew the song, but we sold it.
 There are prettier things to look at than an animal's whatchamacallit.
 You can't go making things – leave Anna alone.
 They are a family.
 They've got the whole world in their hands.

(New York, 1999)⁴¹

41 Basting, "Dementia", *ibid.*, p. 207.

Abstract

Der Aufsatz untersucht die Zusammenhänge von Literatur und Naturwissenschaft am Beispiel der Alzheimer-Krankheit, die in den USA – und nicht nur dort – eine Flut von wissenschaftlichen, belletristischen und journalistischen Texten ausgelöst hat. In diesem diskursiven Feld stehen sich zwei scheinbar unvereinbare Positionen gegenüber: zum einen der medizinische Kampf gegen die eindeutig identifizierbare Krankheit, zum anderen die diskursanalytische Infragestellung des Konzepts Alzheimers selbst. Hier wird ein pragmatischer literaturwissenschaftlicher Ansatz vorgeschlagen, der sich mit der Art und Weise befasst, wie Gegenwartsliteratur eine textliche Realität von Alzheimer herstellt und die Krankheit so in der Alltagskultur verankert. Im Vordergrund der Analyse steht das Problem der Autorschaft im autobiografischen Text. Verglichen werden Probleme und Potenzial des Schreibens über Alzheimerkranke einerseits und die Möglichkeiten des Selbstaudrucks andererseits. Das Hauptaugenmerk gilt Texten von Jonathan Franzen und Sue Miller sowie einem "story telling project" der Gerontologin Anne Davis Basting.