



*On a cool gray Tuesday last November, an audience composed primarily of people with dementia and their caregivers filled every seat of the auditorium space in Seattle's Frye Art Museum. Medical professionals who read this journal might well wonder—if dementia is the problem that these people have in common, why were they drawn to an art museum, of all places?*

# Art, Creativity, DEMENTIA

By Janelle S. Taylor

The most proximal answer, of course, is that this audience had assembled to take part in a daylong symposium on "Art, Creativity, and Living with Dementia,"<sup>1</sup> organized by the Frye Art Museum in collaboration with the Alzheimer's Association of Western and Central Washington,<sup>2</sup> and Elderwise,<sup>3</sup> which offers arts enrichment programs for people with dementia in Seattle. The symposium was the public kickoff event for the Frye's "here:now" program, modeled after the Museum of Modern Art's "Meet Me at the MoMA" program,<sup>4</sup> which offers gallery discussion tours and art-making opportunities for individuals with dementia and their care partners.

Time spent together in the company of nonjudgmental others, enjoying art with the help of a skilled facilitator, allows participants "the chance to suspend or bracket the disease that so dominates their days to create moments of shared joy, learning, and deep engagement."<sup>5</sup> While the "here:now" program is designed with attention to the specific needs of people with dementia, the fundamental need that it addresses is one that they share with all people; as Jo-Anne Birnie Danzker, director of the Frye Art Museum,

put it in her opening remarks: "The key issue we collectively face is how one lives a life of worth and purpose."

Danzker's comment suggests, in turn, a broader answer to the question of what art might have to offer many people affected by dementia. Medical science has not yet succeeded in developing interventions to prevent or cure Alzheimer's or other forms of dementia. Ingunn Moser, dean of a school of nursing in Norway, who conducts scholarly research on care practices, describes the dominant medical stance toward dementia thus: "The therapeutic prospects are understood to be grim... Attempts can be made to control and alleviate symptoms through medication, but... the effect is quite uncertain. There is, thus, little [more] to do other than letting nature take its course. There is nothing to be done, goes the saying."<sup>6</sup> For people already affected by dementia, this "nothing-to-be-done" approach offers little hope and little guidance for how to live as fully and as well as possible for the time that remains.

By contrast, humanistic and artistic approaches demonstrate that there is much that can be done when it comes to making sense of dementia as a human condition. The

1 [http://fryemuseum.org/community\\_article/3989](http://fryemuseum.org/community_article/3989)

2 [www.alz.org/alzwa](http://www.alz.org/alzwa)

3 [www.elderwise.org](http://www.elderwise.org)

4 [www.moma.org/meetme](http://www.moma.org/meetme)

5 Basting, Anne Davis, *Forget Memory: Creating Better Lives for People with Dementia* (Baltimore: The Johns Hopkins University Press, 2009), p. 119.

6 Moser, Ingunn, "Dementia and the Limits to Life: Anthropological Sensibilities, STS Interferences, and Possibilities for Action in Care." *Science, Technology & Human Values*. January 9, 2011. <http://sth.sagepub.com/content/early/2011/01/08/0162243910396349>

past few years have seen a remarkable proliferation of memoirs, novels, short stories, fiction and documentary films, works of photography and visual art addressing dementia and Alzheimer's. For members of the general public who may not (yet) have any particular personal connection to dementia, literary and artistic treatments of dementia as a human experience can help open new avenues for understanding and empathy—and, in so doing, they may perhaps in some measure reduce the fear that surrounds this condition. If in so doing they help people remain engaged with friends and relatives affected by dementia, these artworks may in some small way help alleviate the social isolation and abandonment that so painfully add to the suffering caused by the condition itself.

Perhaps the most readily accessible recent treatment of dementia is the 2007 film *Away from Her*,<sup>7</sup> starring Julie Christie and Gordon Pinsent, based on a short story by Alice Munro. The film presents a moving portrait of Fiona and Grant, a long-married couple, as the onset of dementia and Fiona's eventual move into an assisted-living facility bring new insights as well as painful changes, and the couple embarks upon this next phase of a great-but-complicated love story, in which much has gone unsaid.

Avid readers and book groups may appreciate sensitive treatments of dementia afforded by recent novels. In *The Story of Forgetting*,<sup>8</sup> a novel by Stefan Merrill Block, a young man searches for answers after his mother begins to suffer early-onset Alzheimer's when he is 15 years old. His quest for

understanding leads him deep into a tangled family history of love, betrayal, and genetic inheritance. Another remarkable, moving novel is *Still Alice*,<sup>9</sup> by Lisa Genova (a Harvard PhD in neuroscience). Narrated by the main character, the novel tells the story of Alice Howland, an eminent scientist whose increasing memory lapses are eventually diagnosed as early-onset Alzheimer's, and chronicles the transformations in her family relationships as her husband and two daughters respond in their own ways to her decline—and as Alice herself reevaluates what really matters.

People struggling to come to terms with the onset of dementia in someone close to them may find it helpful to encounter the reflections of others who have trodden a similar path. Those who appreciate poetry will treasure the many jewels included in *Beyond Forgetting: Poetry and Prose about Alzheimer's Disease*, a collection edited by Puget Sound-area poet and writing teacher Holly J. Hughes (who was

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7 *Away from Her*. The Film Farm and Foundry Films; in association with Capri Releasing, Hanway Films, and Echo Lake Productions present; producers Daniel Iron, Simon Urdl, Jennifer Weiss; written and directed by Sarah Polley (Santa Monica, Calif: Lionsgate, 2007).

8 Block, Stefan Merrill, *The Story of Forgetting: A Novel* (New York: Random House, 2008).

9 Genova, Lisa, *Still Alice: A Novel* (New York: Pocket Books, 2007).

continues

among the participants in the Frye's symposium), with a foreword by Tess Gallagher. Hughes, who was moved to assemble this work in the wake of her mother's death from Alzheimer's disease, seeks to show how the transformative power of poetry can enable one to move "beyond forgetting," and beyond the stereotypical portrait of those affected by this condition, to see "not just the tragedy of Alzheimer's disease, but its odd dignity, its unlikely beauty."<sup>10</sup>

Adult children coming to terms with the onset of dementia in one or both parents may look to several recent memoirs for wonderfully poignant, compassionate and heartbreakingly sad—but occasionally very funny—accounts. Two of the best are, perhaps not surprisingly, the work of gifted novelists: *The Story of My Father*,<sup>11</sup> by Sue Miller, and a short essay titled "Mother Tongue," by Ian McEwan.<sup>12</sup>

Elinor Fuchs, a Yale professor of theater, is author of the wonderful memoir *Making an Exit: A Mother-Daughter Drama with Alzheimer's, Machine Tools, and Laughter*.<sup>13</sup> *Memory Lessons: A Doctor's Story*,<sup>14</sup> is Jerald Winakur's account of how, after many years spent helping patients and their families cope

with the challenges of aging, he experienced his own father's decline into dementia. Freelance reporter and nonfiction writer Lauren Kessler wrote an account of the year she spent as a low-level nursing aide in a dementia care facility, partly as a way of coming to terms with her own regret at how she had dealt with her mother's decline and death. The eye-opening and deeply compassionate result is her book, *Finding Life in the Land of Alzheimer's: One Daughter's Hopeful Story*.<sup>15</sup>

Photographer Judith Fox offers an unblinking but loving portrait of her husband, who is affected by Alzheimer's and for whom she cares, in a book whose title refers to the phrase that the two of them long used to express to each other their reaffirmation of their wedding vows: *I Still Do*.<sup>16</sup>

First-person accounts authored by affected individuals offer insight into the lived experience of dementia—an experience that encompasses transformations in relationships and self-conceptions, as well as cognitive, sensory and emotional changes. These accounts also stand as shining examples of what a person affected by dementia or Alzheimer's disease may yet achieve and create—because of, as well as despite, the difficulties that the condition presents, particularly with regard to language and cognition.

Thomas DeBaggio, whose 2002 book, *Losing My Mind: An Intimate Look at Life with Alzheimer's*<sup>17</sup> was among the first

examples of such works to appear, interweaves descriptions of the author's life in the present, with memories of his childhood, and snippets and clippings from scientific research on Alzheimer's; subsequently, DeBaggio authored a second book, *When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's*.<sup>18</sup> Another book, *Alzheimer's from the Inside Out*,<sup>19</sup> authored by retired psychology professor Richard Taylor after his diagnosis with "probable Alzheimer's," offers a more analytic and critical, though still highly personal, account.

In terms of sheer beauty of writing, few books can compare with the works of Floyd Skloot, who for years has been living with dementia that resulted from a viral infection contracted while he was still quite young and that left him with brain damage. In the *Shadow of Memory*<sup>20</sup> is a stunning and revelatory collection of essays addressing various aspects of the experience of "thinking with a damaged brain." Skloot's subsequent book, *A World of Light*,<sup>21</sup> recounts the transformation of his long-troubled relationship with his mother in the wake of her own dementia due to Alzheimer's disease.

Picking up on the medical phrase, "an insult to the brain," Skloot notes in one of his essays that "there is a long tradition of avenging insults through duels or counterinsults... So I write. I avenge myself on an insult that was meant, it feels, to silence me by compromising my word-finding capacity, my ability



10 Holly J. Hughes, ed., *Beyond Forgetting: Poetry and Prose about Alzheimer's Disease* (Kent, OH: The Kent State University Press, 2009), p. xxiv.

11 Miller, Sue, *The Story of My Father: A Memoir* (New York: Random House, 2004).

12 McEwan, Ian, "Mother Tongue," [www.ianmcewan.com/bib/articles/mother-tongue.html](http://www.ianmcewan.com/bib/articles/mother-tongue.html)

13 Fuchs, Elinor, *Making an Exit: A Mother-Daughter Drama with Alzheimer's, Machine Tools, and Laughter* (New York: Metropolitan Books, 2005).

14 Winakur, Jerald, *Memory Lessons: A Doctor's Story* (New York: Hyperion, 2009).

15 Kessler, Lauren, *Finding Life in the Land of Alzheimer's: One Daughter's Hopeful Story* (New York: Penguin Books, 2008).

16 Fox, Judith, *I Still Do... Loving and Living with Alzheimer's* (Brooklyn: PowerHouse Books, 2009).

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

18 DeBaggio, Thomas, *When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's* (New York: Free Press, 2003).

19 Taylor, Richard, *Alzheimer's from the Inside Out* (Baltimore: Health Professions Press, 2007).

20 Skloot, Floyd, *In the Shadow of Memory* (Lincoln: University of Nebraska Press, 2003).

21 Skloot, Floyd, *A World of Light* (Lincoln: University of Nebraska Press, 2005).

to concentrate and remember, to spell or conceptualize, to express myself, to think." Skloot then describes the tortuous, oblique, agonizingly slow process by which he writes, and concludes that "every time I finish an essay or poem or piece of fiction, it feels as though I have faced down the insult."<sup>22</sup>

This insight, that creative self-expression is vitally important for the selfhood that dementia threatens, lies at the core of arts-based therapies for people with dementia. These take many forms; some focus on writing, others on visual art, theater, song, and more. One notable example is TimeSlips, the storytelling therapy developed by Anne Davis Basting, in which trained facilitators work with groups of people with moderate to severe dementia, to collectively and collaboratively compose original stories in response

to striking photographs that serve as prompts. The act of making these stories draws out people, engages them in meaningful activity with others, uses the capacities they still possess, and creates something of value that can be shared with others. TimeSlips stories have been posted on the web, shared in touring exhibits, and even developed into plays that have been performed.<sup>23</sup>

This conjunction of art and care brings us, finally, to the simple but very powerful point that scholars in my own field of medical anthropology emphasize: Care practices themselves can be a site of creativity, innovation, and meaning-making. One of the cruelest implications of the "nothing-to-be-done" view of dementia is that the difficult, vital, important work of caregiving counts as "doing nothing." The noted psychiatrist and

medical anthropologist Arthur Kleinman counters this in his recent writings about what he has learned through caring for his wife, Joan, after the onset of her dementia. He describes caring as "a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human... caregiving is one of those relationships and practices of self-cultivation that make us, even as we experience our limits and failures, more human. It completes (not absolutely, but as a kind of burnishing of what we really are—warts and all) our humanity. And if... by building our humanity, we humanize the world, then our own ethical cultivation at the very least fosters that of others and holds the potential, through those relationships, of deepening meaning, beauty, and goodness in our experience of the world."<sup>24</sup> ■

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22 Skloot, *In the Shadow of Memory*, p. 11.

23 For a longer discussion of TimeSlips, as well as a review of other arts-based therapeutic approaches, see Anne Davis Basting's *Forget Memory*.

24 Kleinman, Arthur, "Caregiving: The Odyssey of Becoming More Human," *The Lancet*, Volume 373, Issue 9660, Jan. 24, 2009; 292-293.

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