Rosa (a pseudonym) is a 92-year-old retired professor with midstage Alzheimer’s disease who lives in a specialized dementia care unit. She moves purposefully and slowly with the help of a walker to and from her bedroom and her favorite seat in the dining area. Although not one to initiate conversations with other residents or staff outside of meal times (she is often tired and prefers the privacy of her room to the openness of the dining room and parlor), she always has a warm smile. If you join her at her table, she will ask you to tell her about your life, your schooling, and your future plans. One day, when I asked her to describe herself to me, she thought for a moment and said she was a “would-be school teacher” who was looking forward to going to college and starting a family. She said she really enjoyed working with young children and wanted to help them get a good start on their lives. Although Rosa has two grown children and several grandchildren who visit her often and whom she enjoys seeing, it was the future on this day and time—not the past or the present—that held enormous possibilities for her and gave her great joy to consider and talk about.

Words like “possibilities” and “future” often are missing in the dementia discourse unless used in the context of finding a cure or in the need to plan for care as the disease progresses. Dementia frequently is framed as a gradual loss of self whereby the person slowly transforms from a spouse, parent, and/or friend into an unrecognizable stranger. Metaphors that include darkness or having the lights suddenly turned off or being stolen from within by an invisible robber reinforce the point that from the moment of diagnosis, a person with dementia often is viewed as ceasing to grow as a person and instead is thought to become more and more a shadow of his or her former self.

Kitwood (1997) used the phrase “malignant social psychology” to describe the way in which people with dementia are stigmatized, infantilized, and devalued because of their illness. Sabat (2006) uses the term “malignant positioning” to further describe the way in which the person with dementia is positioned and viewed as “defective” and “unable” by caregivers and health care professionals who, in contrast, position themselves as “healthy” and “able.” Such devaluation and negative positioning lead to accepted views that people with dementia are incapable of expressing “real” concerns or fears; are not in a position to legitimately counter depersonalizing or troublesome encounters with care providers or others, such as when care providers talk about the person as if he or she were not present or say negative things about the person; or lack awareness of self.

In Rosa’s case, caregiving staff who talked to me about who they thought Rosa was at present and what they believed was important to her now said she viewed herself as a “tired, useless old woman” whose main concern these days was the regularity of her bodily functions. Certainly, Rosa does have times when she views herself as tired and useless, especially in the restrictive environment of a secured care unit. And she may very well be concerned with her body because few, if any, things are within her control at this point in her life. Rosa’s example is not meant to romanticize or ignore the medical realities of the Alzheimer’s disease and the physical and cognitive declines that will continue until her death. However, on the day in which Rosa and I spoke, and probably on many other days as well, Rosa had a very definite present and a future that brought meaning to her life.

How do we understand and address the complexities of dementia and from whose perspective? Three recent books critically explore often overlooked aspects of this bigger world of dementia, such as possibilities and meaningful futures for those with the disease and avenues for...
positive change for the structures that frame the experience. The first book, Lisa Snyder’s Speaking Our Minds: What It’s Like to Have Alzheimer’s (2009), is a revised edition that builds upon the book’s original release 10 years prior. It features the stories of seven people with Alzheimer’s disease (a chapter for each) who talk candidly about their fears, challenges, social support systems, feelings of loneliness, strategies to compensate for various losses, and how they find joy in their lives. The book is framed by two chapters in Snyder’s voice alone—a beginning chapter, “Listening,” which provides a brief introduction to Alzheimer’s disease, a statement on the importance of giving voice to experience, and sketches of the people presented in the book and a concluding chapter, “Responding,” which addresses current movements in care and treatment of Alzheimer’s disease. The appendix has a thoughtful list of discussion questions and selected resources.

The focus of Speaking Our Minds, however, is the middle chapter, “Speaking.” Except for one individual, Bill, whose expressive aphasia made it necessary for Snyder to edit his words, each person’s story is told in his or her own voice (in bold type, sans serif font) with contextual background information and other relevant details by Snyder in regular print. The chapter on Jean, for example, begins with Snyder’s description of how the two met. Jean then shares some of her views on memory: “The memory is a loss that is painful because you know you have something in there about whatever the issue is and you can’t get at it. There is embarrassment when I want to say ‘ocean’ and I can’t think of the word” (p. 62). Snyder’s paragraphs that follow touch upon the nature of language changes with Alzheimer’s disease and elaborate on some of the fears and challenges Jean expressed. Other interviews highlight larger social issues, such as how dementia is framed and treated by society. In the chapter on Bea, who was struggling with visual agnosia or the ability to recognize objects and was increasingly reluctant to leave her apartment, Snyder writes: “My interview with Bea pointedly reminded me of how quickly we measure disability, deficits and differences at the risk of overlooking ability, strengths and commonality.” (p. 34). Bea’s strengths included the humor with which she addressed her challenges, such as needing help with eating, and her decision to keep moving forward, no matter how difficult. As Snyder points out, stories of acceptance are often framed by outsiders as stories of loss, thereby reinforcing a malignant position.

As poignant as the stories are, I admit that when I first began reading them, I found myself falling prey to the same stereotype that Snyder’s book is meant to challenge: that people with Alzheimer’s disease are not truly capable of understanding their experience. I caught myself thinking, “Surely this is not typical. Surely these folks are at the beginning of the disease. How can they be so positive? How can someone plan a trip to Europe when they have Alzheimer’s disease? Can people with dementia really be that self-reflective?” It became apparent to me as I jotted these thoughts down in the book’s margins that the type of biased thinking I was expressing was exactly what makes Snyder’s book so important. It is a reminder that stereotypes, stigmas, and misconceptions associated often frame our understanding of dementia; people with dementia are reflective, have self-awareness, and have a voice that “counts” and that needs to be heard.

Another book that challenges conceptions of what is possible with memory loss is Anne Basting’s Forget Memory, but with a slightly different emphasis than Snyder’s. Basting’s book effectively argues that the cultural emphasis and importance we place on memory overshadows the enduring quality of imagination, which is often not considered in dementia practice. Early in the book, Basting provides a fascinating overview of memory, from theories of how memory works to a history of memory ranging from Greek epic poems to modern computer games. In reference to Western civilization’s link between memory and immortality, Basting writes early in her book, “As we focus our labor on the act of remembering, both for ourselves and for future generations, we also exacerbate the shame and fear surrounding forgetting and the human frailty, dependency and mortality with which forgetting is linked” (p. 23). She then presents some excellent and very entertaining descriptions of popular tropes of memory loss in films and television. On screen, memory loss has three general causes: physical trauma (“50 First Dates,” “Memento,” “Gilligan’s Island”), emotional trauma (“Nurse Betty”), or by oppressive government (“Total Recall”). Almost as rare as dementia as the subject of movies are the older people who experience it. Even when dementia is the topic, the focus frequently is on who the person was prior to the disease compared with the tragedy of who they have become, the before and after.
Of special importance in Basting’s book are the several chapters dedicated to programs that awaken imagination and explore what is possible for people with dementia. She writes, “The programs I outline emphasize the value of being in the present moment. They emphasize memory as relational, as existing between people not as belonging to one person or another. They offset our fears of meaninglessness by filling that void with meaning and providing the tools for making it” (p. 69). Programs include StoryCorps, Memory Bridge, TimeSlips, Meet Me at MOMA, Elders Share the Arts, songwriting groups, the visual arts, and other programs that Basting brings alive through the voices of participants and program facilitators. She does not simply present a series of success stories or provide readers with a quick recipe for how to replicate these programs at home. Instead, she gives each program a rich thoughtful discussion that connects the theoretical underpinnings (e.g., why does this type of storytelling work), with the key participants in ways that can be funny and incredibly poignant and moving.

Finally, Basting concludes with a list and discussion of 12 things that people can do right now to improve the lives of people with dementia: (a) insist on complex stories of dementia, (b) embrace the gray, (c) advance the dementia advocacy movement, (d) think creatively and fight for better options, (e) think and act in coalition, (f) value listening, silence, and the present moment, (g) understand that memory is more than individual property, (h) healing is bigger than memory, (i) assert the value of forgetting, (j) insist that it is normal for young people to care about aging, (k) open avenues for meaning-making, and (l) do not be afraid of reducing fear. The appendices include descriptions and contact information for various creative programs for people with dementia; a list of images and stories of dementia (e.g., novels, plays, memoirs, films); and a timeline of the recent history of dementia to include the debut of public service announcements from the Alzheimer’s Association, approval dates of various dementia medications, key novels and films, and other events that shape how dementia is experienced and understood.

The third, Anthea Innes’s Dementia Studies (2009), provides a critical in-depth look at the political, economic, social, and cultural issues that frame and influence health, illness, and knowledge of dementia from a social sciences perspective. Each chapter begins with a page-long summary and ends with a brief conclusion and suggested readings, which helps the reader track the many arguments and issues surrounding dementia studies. The book is well balanced and thorough in discussion of issues such as the twin stigmas of old age and dementia, the complexity and challenges of person-centered care (PCC), the cultural context of caregiving, and the ideals for advancing dementia research. For example, Innes does not simply present and support the PCC approach as described by Kitwood (1997) but creates an internal discussion through the work of Davis (2004) and McCormack (2004) and others that causes one to pause and reconsider—and perhaps dismantle—some common concepts that have been absorbed in the dementia lexicon. Does PCC as described by Kitwood ignore the many challenges faced by caregivers in their basic care functions and create a potentially unattainable goal that could lead to caregiver despair and guilt? Although Innes does not argue this, she does effectively present work that points to the need to further define and research PCC practices and their effect on caregivers and people with dementia. Regarding care in general, Innes argues that a major barrier to achieving the ideal of PCC is the “bed and body” approach. Task-centered care (e.g., bathing and feeding) takes less time to complete and is more valued by management than personalized care for which there is no incentive for the marginalized care workers. Not only must the reality of costs and rewards be considered but taking a larger view of PCC as “relationship centered care” can also help to acknowledge and address the potential challenges to achieving truly personalized care.

Innes’s discussion of caregiving is particularly effective and thought provoking, spanning more than just the chapter on caregiving itself but extending into the following chapter on dementia in cultural contexts. Issues of power (e.g., the low status of dementia caregivers and the people for whom they care), place (home, care facility), and cultural framework (e.g., who should provide care, the meaning that dementia has for a given group, including people from various geographic regions, and the professional care cultures of service providers) are all explored in detail. Although Innes cites a few small examples of societies in which dementia is not stigmatized, she writes, “As long as dementia is misunderstood and those with dementia stigmatized and marginalized, those who work with them will similarly be marginalized and devalued” (p. 94).

Innes concludes by introducing a model of dementia studies informed by theory, context (social, political, economic), care practices (family and paid), and research. Like Snyder and Basting, Innes stresses the importance of challenging assumptions about
the nature of dementia and models of care and turning more toward the experiences of those with dementia and their caregivers as sources of knowledge. In doing so, all the three books bring “possibilities” and “future” to people with dementia.

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