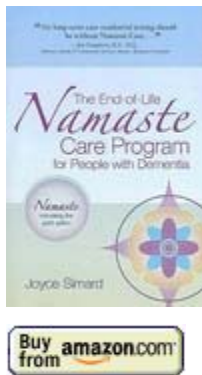


Validating Spirit in End-of-Life Dementia Care

A review of



The End-of-Life Namaste Care Program for People with Dementia

by Joyce Simard

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Reviewed by

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Death is common; *dying* is not. Myriad paths lead people to a banal terminus of the physical existence. From sudden accident or injury to prolonged suffering, it's the time before the end that concerns people. Will I be in pain? Will she know I'm here? Does he have a sense of closure?

End-of-life studies reveal that most people say they want a "good death," but what this generally means is that they want a good *dying* (e.g., Glaser & Strauss, 1968; Kübler-Ross, 1969). Perceptions of acceptable—even honorable—dying vary across time, cultures, situations, and persons (Copp, 1998; Holloway, 2006). In Western cultures, coming to a sudden, unexpected end is not considered a good

dying, unless the end is pain free and one has experienced a productive, long life. Drawn-out suffering toward one's death is viewed as generally undesirable, unless the suffering is endured with courage and the person appears to be elevated by the experience (e.g., by faith; Gelo, O'Brien, & O'Connor, 1997). End-of-life research reveals that these are examples of people's perceptions of dying (Gelo et al.; Hopkinson, Hallett, & Luker, 2003).

In her recent book *The End-of-Life Namaste Care Program for People with Dementia*, Joyce Simard demonstrates that she is an expert about good dying. The focus of her work is a path-breaking program for end-of-life dementia care in the United States. The name of her project reveals the homage she pays the human spirit: *namaste*. Simard moves skillfully between recommendations for oversight of namaste care; descriptions of hospice decisions under Medicaid/Medicare guidelines; narratives about active dying among individuals with dementia; and heralds to announce persons' rights to die in dignity, validation, and peace. Indeed, this work is very much in keeping with the hospice tradition begun by Dame Cicely Saunders (1959) for care of terminally ill patients, and Simard emphasizes a call to recognize hospice as a care alternative in end-stage dementia care. This is a critical point (Mitchell et al., 2007).

Simard's book is organized to afford easy study by long-term care administrators, nurses, social workers, nurse assistants, and other caregivers who might want to understand active dying in late-stage dementia. Even her terms reveal namaste as she invokes a progressive, person-centered language that renames "caregivers" as "care partners" and "carers." And while the focus is end-stage care of residents with Alzheimer's disease (or other dementia) who are in long-term care facilities, Simard acknowledges the breadth of her approach by way of its label: namaste. She aims "to honor the spirit within" (p. xiii) and "to acknowledge the person, not the disease" (p. xiii). Via the author's tone and the book's content, a reader can easily map the spirit of this care program back to its origin: the Hindu word for one being honoring another's essence. Simard's guide is also in keeping with Kitwood's (e.g., 1997) person-centered techniques in dementia care and with more recent guides for integrating practical care with validations of

personhood (Brooker, 2007; Castleman, Gallagher-Thompson, & Naythons, 1999). Her approach focuses on the administration of, staff for, and atmosphere imperative in namaste care. And she does all this very well in fewer than 200 pages!

Readers of *The End-of-Life Namaste Care Program* will not find theories of dying in the book. This is a practical guide for administrators, staff, and other care partners who wish to understand and implement namaste care for someone with end-stage dementia. Simard is clear about her goals—providing an overview of the approach in the first three chapters of her book. I found Chapter 2 to be the most critical as I thought about whether to try this care approach or not.

My kudos include a few suggestions for the next edition—a book for which there is bound to be a continuing need, as Alzheimer's disease becomes epidemic in the third millennium. Infusing more mapping of process onto daily scheduling (such as more about how namaste care staff and “regular” floor staff can cope with transport back-and-forth for meals, toileting, and grooming; Simard, 2005) might improve the functionality of the book for care partners who collaborate across a standard skilled nursing floor and a namaste care room. While this mapping of process over time is present in Simard's (2005) article about namaste care, some readers of the book might not be aware of the previous case study about Matthew. Also, exceptionally pragmatically, a bread maker (p. 69) should be approved by a facility's administration (as regards fire code) and by dietary services (with respect to its use in specific residents' diets). And it is imperative for readers of Simard's guide to get marbles and similar small objects into sealed shatterproof containers (pp. 89, 163), as objects like these are prone to be placed in the mouth by persons with moderate to severe Alzheimer's disease. I mention this *for the reader's benefit*, rather than Simard's, because her book's excellence tells me that she has already “secured the marbles” at her facility.

Something to expand in a later edition of this book would be consideration of culture of care and family wishes. Simard touches on these in several places (e.g., use of cultural music, p. 68; examples of orientation to person, p. 80; and sensitivity to one's family culture, p. 112), but attunement to family, ethnic, and cultural differences about

perceptions of dying could be discussed in more detail within a culture-of-care framework (Brooker, 2007; Leininger & McFarland, 2006). I enjoyed that Simard infused sentiments about culture-of-care into her vignettes and examples, but explicit goals and recommendations might be helpful, too. One of the greatest strengths of Simard's work is in merging frameworks from national efforts in palliative care into her practical guide without making them cumbersome for the novice reader to understand (e.g., National Hospice and Palliative Care Organization).

Do I favor this book? I have already suggested Simard's book to two colleagues, at different institutions, who teach courses on death and dying. Moreover, I'm certain to reference the book in my own course on life-span development. My conclusion is that Joyce Simard's book should be on every dementia care specialist's reading list this year.

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