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Lamenting the Failure of Long-Term Care

Kathleen Vidmar

Robert L. Kane and Joan C. West: *It Shouldn't Be This Way: The Failure of Long-Term Care* (Vanderbilt University Press, 2005)

“Packing up our mother’s few remaining possessions, we felt that her life should mean more than these fragments,” say brother and sister co-authors Robert Kane and Joan West. Their mother, Ruth Kane, suffered a stroke at age 84, and lived the final three years of her life in various long-term care settings. Robert Kane, a geriatric physician and researcher, and West, an elementary school teacher, recount the final years of their mother’s life, and in the process of telling their story, attempt to offer practical guidance to others who are navigating the world of long-term care for the first time.

As it happens, Kane and West wrote this book for people like me. Shortly after I was asked to review their work, my own mother suffered a severe hemorrhagic stroke to her right brain. Only 59 years old, my vibrant, energetic mother was rendered utterly dependent, losing all sensation and mobility on the left side of her body from her shoulder down. After cranial surgery and a brief stay in the hospital, she has lived the last two months in a Transitional Care Unit. Happily, my mother is recovering beautifully from her stroke. She is regaining sensory and motor function, and will be leaving the world of long-term care and returning home as I write this review.

My personal experience lead me to read Kane and West’s book with great interest. The book promised to be part memoir, part practical guide, as the siblings recounted each step of their mother’s journey. From the event of her stroke, through relocation, rehabilitation, assisted living, and their mother’s final days in a Nursing Home, the



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authors outline their experience navigating through a matrix of insurance rules, hidden costs, and federal regulations.

They describe an environment where poor communication and caregiving without compassion are commonplace. Most significantly, they reveal a care system ordered toward metrics and profit rather than what was best for their mother, a system that seems utterly incapable of appreciating the profundity of what it means to care for those among us who are facing their own mortality.

At the end of each chapter, Cane and West offer practical advice on traversing what they describe as a tragically broken system. These sections of the book are a crash course in what my mother calls “personal advocacy,” understanding your rights and how to assert them over and against a care system that could quite literally “care less.” The final chapter of the book calls for reform, demanding the dramatic reorganization of Medicare and Medicaid, and changes in the communication and funding structures in hospitals, insurance companies, and long-term care facilities. The authors advocate for higher wages for those caregivers who work in closest proximity to patients, and end by calling for the formation of a coalition of interested medical practitioners and laymen to lobby Congress.

For me, *It Shouldn't Be This Way* provided a technical introduction to the world in which my mother was now living. For someone unversed in hospital jargon, unaware of the inner-workings of insurance companies and federal programs, and generally naïve to the pitfalls of the long-term care scene, this book could prove to be very helpful.

But I wanted more. Cane and West do not promise anything more than a secular, technical analysis of the state of long-term care in the United States, and they deliver their conclusions in these terms. In the end, they advocate for the creation of a system that more justly adjudicates between the rights of the person over and against the rights of the institutions. In doing so, they betray a foundational belief that this kind of procedural response will have the power to resolve the tragedy of their experience.

With all due respect, I doubt it. Our long term care system does not exist in isolation—its problems are the fruit of underlying *cultural* problems that are born out in the authors’ experience, and the result is heart-rending. As I reflect on my own experience with my mother, I wanted someone to speak into my experience on *this* plane. I wanted Cane and West and to talk about what it meant to them that their family was scattered across the



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country. After their father's death, their mother moved out of their family home in New York and took off for Florida with a new lover. With the locus of their family life gone, Cane and West did what most everyone in the US does—they moved to the places that were most advantageous to their careers. Their mother did *not* have strong connections to her community in Florida, and much of the difficulties in the early days after her stroke were clearly exacerbated because none of them were rooted in a *place*. (I mean “place” with all of the force that an Aristotelian/Wendell Berry-ian context can provide!)

I wanted the authors to tell me more about their mother's extreme aversion to medical care, her great fear of becoming disabled, and her wish to be euthanized if she were ever to become so. In her view of the world, she did not believe that her life would be worth living if she were dependent; clearly, the knowledge of her adamant perspective on this matter was a cause of great grief for her children throughout the ordeal. Ruth was not a religious woman. Indeed, through the lens of a secular worldview, old age, decline, and death are an absurdity. If Ruth had been grounded in a perspective of the human person founded in our ability to give and receive love (as opposed to an identity rooted in our ability to exercise control), how might her perspective on her own life have been different?

Much more could be said here, but my central question is not so much directed to the authors, as to all of us. In the United States, to have a right, one must be able to claim it. The majority of the advice given by Cane and West is about just this—self-advocacy in the form of claiming rights within the context of our long-term care system. My question is this: what does it mean that within the socio-political cultural context of the United States, our conception of “rights” carries forward an inherent vulnerability for anyone who *is unable to claim these rights for themselves*. So long as our paradigm of human interaction is conceived in this manner, we will always have reasons to say, “It shouldn't be this way.”

Kathleen Vidmar holds a B.S. in Liberal Arts/Pre-Medicine from the University of North Dakota and an M.T.S. in Biotechnology and Ethics from the John Paul II Institute for Studies in Marriage and Family. She has returned to her native North Dakota where she has served both the University of Mary in Bismarck and North Dakota State University in Fargo.

