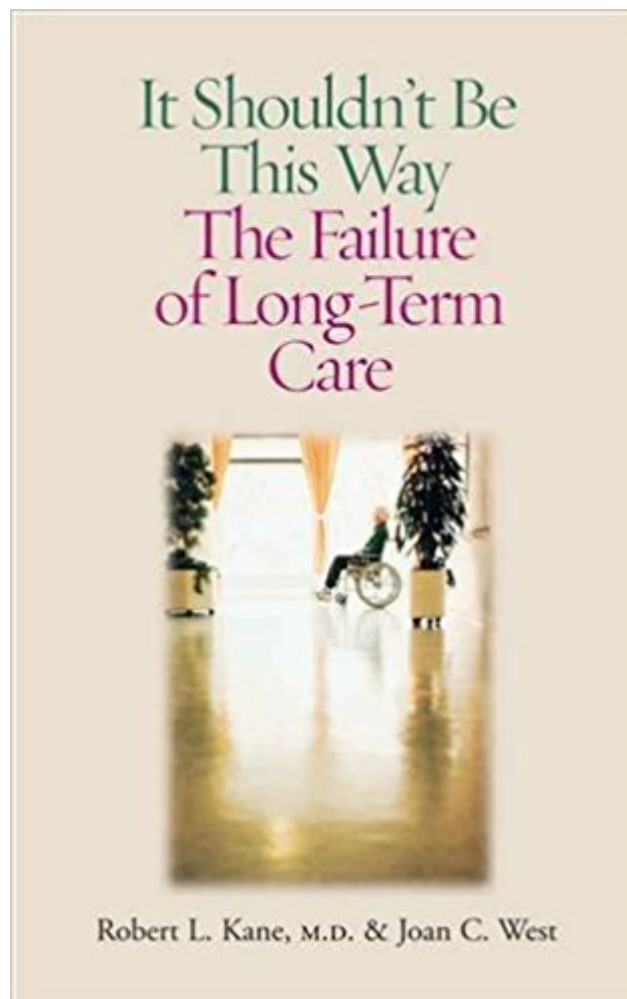


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# It Shouldn't Be This Way: The Failure Of Long-Term Care



## Synopsis

The failure of long-term care is the country's best-kept embarrassing secret. Almost every adult in the United States will either enter a nursing home or have to deal with a parent or other relative who does. Studies show that 40 percent of all adults who live to age sixty-five will enter a nursing home before they die, while even more will use another form of long-term care. Part memoir, part practical guide, part prescription for change, *It Shouldn't Be This Way* is a unique look at the problems of long-term care. Robert L. Kane, a highly experienced physician and gerontologist, and his sister, Joan C. West, tell the painful story of what happened to their mother after she suffered a debilitating stroke and spent the last years of her life in rehabilitation, assisted-living facilities, and finally a nursing home. Along the way, her adult children encountered some professionals who were kind and considerate but also many frustrationsâ€”inadequate care and the need to hire private duty aides, as well as poor communication and lack of coordination throughout the system. The situation, they found, proved far more difficult than it needed to be. As the authors recount their mother's story, they impart various lessons they learned from each phase of the experience. They alert those who are confronting such situations for the first time about what they will likely face and how to approach the problems. Closing with a broader look at why long-term care is the way it is, they propose steps to make necessary reforms, including the development of national organizations to work for change. Their message to families, care professionals, and policy-makers could not be more urgent.

## Book Information

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## Customer Reviews

"A common sense book that is part memoir, part guidebook, and part call to arms."â New York Times

"An extraordinary blend of personal and professional vision on a problem that has both policy and spiritual dimensions. This book does what a support group does: tells you that you are not alone. It helps you interpret your experience, understand it, put words to it, and crystallize your understanding, both emotional and intellectual. "Many of the authors' insights will be useful to caregivers - especially those caring for elderly parents - who need to know:- That hospitals have their own institutional needs at heart, not your parents'- That discharge planners are not your friends- How to evaluate nursing homes- When and how to conduct discussions about DNR (do not resuscitate) wishes "These and other practical but crucial issues are dealt with in clear detail that will help people know how to act and talk when they are in similar situations. Beyond these practical things, Kane and West illuminate the emotional landscape of parental care - even harder issues to prepare for and to talk about. "It's a tremendously worthwhile book, with enormous potential value both to lay people and policy professionals." --Deborah Stone, Research Professor, Department of Government, Dartmouth College

I just starting to read this book last night. My brother passed away after 4 months in a regular hospital/ then to a long term acute care facility/then to a subacute care facility/then back to a regular hospital. He had cancer and Guillain-Barre, a paralysis, also COPD and a heart valve. A lot going against him, and he was 77. This was a gut-wrenching experience for him, his family, and his friends. I am very intested to learn what this doctor and his sister have to say about the long term care experience. My other brother, age 72, is now in a long term care facility with Parkinson's.

Mandatory reading for developers, administration and care professional of senior living industry

Yes

One of the best books I've read! ...and not just because I had to for class! The perfect book for a gerontologist! Thank you UMASS Boston for this book!

I read this book after my roommate, who studies gerontology, passed it on. It was part of his coursework. As someone who is getting older, the take-away (which, I suspect, is intended to be

broader and inform the medical and elder-care community) is not to move far away from your family in retirement. Unfortunately, what the writer doesn't acknowledge is the way in which Ruth was part of a systematic relocation of elders from the crowded Northeast to Florida and Arizona, supported by millions of Federal dollars for infrastructure in the 60's and 70's. Everything the author describes would have happened differently had his mother aged in place.

It met the need and arrived on time. I didn't really care for the content. One of a million stories nothing new. I bought it second hand and used it was.

My parents are just entering the phase of needing some kind of elder care. This book was a big help, since a geriatric specialist was the co-author and son of the woman this book was about.

I work in a Long Term Care Facility. This book is extremely unfair to the staff who are trying their very best to provide a quality life for the elderly whose family are unable to provide care. The "mother" discussed by the authors is a very challenging individual. She has behaviors that do not respond to love and care. She is the type of person who causes staff to become burnt-out. And then it is so typical that as staff are attempting to provide a safe environment, family show up and complain about the situation. We do not "throw away" elder adults that are angry and abusive. Staff, including myself are in this job because we love older adults. We do not make much money. We could have gone into sales or technical fields and doubled our salaries. I am very proud of caregivers who spend their day changing diapers interspersed with giving hugs and reassurances to older adults who are lonely. There was not one nice thing said about staff in this book written by very angry family members who undoubtedly are feeling guilt over not being able to care for their mother at home.

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