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 frustrations— 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.

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Customer Reviews
I recommend this book highly, having read it shortly after my father had to go into a nursing home. It resonated completely with my overall experience and made me more assertive in pushing for changes at the home where my father resided. Like the authors, I have experience with medical practice, as I’m a professor teaching medical students, but encountered the same frustrations that Dr. Kane describes. The lists of questions to ask and things to be cautious about at the end of each chapter are great resources for anyone who is, or may become, responsible for the care of an aging relative. Dr. Kane’s sad, but engaging, story of his mother’s experiences during her declining health illustrates the many difficulties in changing a system of care for the elderly that has depended too much on the good will and dedication of underpaid and often inadequately trained staff at assisted living and nursing homes. The problems Dr. Kane describes happen far too often.

This book should be mandatory reading for every healthcare professional and for all nursing students. It is excellent for anyone dealing with or who will deal with aging parents. I continue to buy copies and share with anyone I find enduring the journey through long term care. Our family has just finished our journey through the failed system. I have personally had 20 years experience as a nurse in long term care but nothing could have prepared us for the journey. Unfortunately nothing can take away the pain and suffering our father endured for those months in long term care facilities. However this book put in words many of out thoughts and much of what we experienced. I have read it several times and read it out loud to anyone present when we were trapped in similar circumstances. Our journey was similar in many ways which is tragic. Everyone with parents still living should read this book. We must move together to make a difference and change this failed system.

We who are aging do not do with with planning. I think we all hope to go with that heart attack in our sleep. We all expect to be like Moses, who was functional all the way to his death at 120. Unfortunately, as we age our frailty and difficulties increase without warning. At least, without warning which we heed. This book opens one’s eyes. It is a must read for everyone who is getting older each day - that is all of us!

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.

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.

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.

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!

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

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