

ELDERCARE

CONFIDENTIAL

CAUTIONARY TALES FOR ADULT
CAREGIVERS AND CARETAKERS
OF PARENTS AND SPOUSES

Chris Cooper



INDIE BOOKS
INTERNATIONAL

CONTENTS

SECTION I: The Great Eldercare Dilemma	5
Chapter 1 Debunking the Shady Acres Myth	7
Chapter 2 Confessions of an Eldercare Advocate	25
SECTION II: What to Beware with Eldercare	33
Chapter 3 The Worst Medical Mistakes	35
Chapter 4 The Worst Psychological Mistakes	47
Chapter 5 The Worst Social Mistakes	61
Chapter 6 The Worst Environmental Mistakes	71
Chapter 7 The Worst Legal Mistakes	97
Chapter 8 The Worst Financial Mistakes	111
SECTION III: Eldercare that Works for All	131
Chapter 9 Concerns About Long-Term-Care Insurance	133
Chapter 10 How to Hire a Fiduciary to Manage the Care	149
APPENDIX	161
Acknowledgments	163
Resources	165
About the Author	171
Index	173

SECTION I

The Great
Eldercare
Dilemma

CHAPTER 1

Debunking the Shady Acres Myth

What is the Shady Acres myth? Let's separate fact from fiction.

There is a common misconception of an eldercare Shangri-La, a lovely place to take Mom for her declining golden years. With a little searching, the children or spouse will find a healthy, comfortable, and mostly government-paid-for idyllic home, complete with rocking chairs and lemonade. "Won't Dad just love it here!" All will be taken care of and the children or spouse will be relieved of messy caregiver and caretaker decisions and wrangling.

Caregivers and caretakers faced with challenges of eldercare quickly discover the United States is in crisis. With life expectancy rising and seventy-seven million baby boomers entering retirement age,

middle-income American seniors and their family caretakers are facing enormous challenges. They look in vain for their Shady Acres.

Sorry to say, Shady Acres does not exist. Even if it did, you probably could not afford it. Most middle-income Americans are unaware of the crucial fact that the government does not generally cover long-term-care expenses. This can be distressing for the six million Americans age eighty-five and older, a number that will shoot up to more than fourteen million in 2040, according to the U.S. Census.

If a spouse needs long-term care, that is one thing, but if the care is left to one or more of the children, then that can be a sticky situation. There is no simple solution for the sandwich generation that is taking care of children and parents. As writer Jennifer Braunschweiger noted on the More website (<http://www.more.com/eldercare>): “There’s no prenup for eldercare, no contract in which we lay out clearly what tasks we are willing to do, how much time and money we are willing to spend and what responsibilities, if any, lie beyond the scope of the agreement.”

THRUST INTO THE ROLE OF FIDUCIARY

This book is for the caregivers and caretakers who are often thrust into the role of fiduciary, either by legal appointment or by assuming the role because of their relationship to the elderly person who needs caretaking. Typically, this is a close relative, like a parent.

This is a guide to help those facing eldercare issues, such as spending other people's money even if it is on the elderly person, making medical and legal decisions for the elderly person, and the implications of substituted judgement (the standard to be used by surrogate decision makers who have specific knowledge of the elderly person's values and wishes pertaining to health care and other choices).

Eldercare also includes dealing with myriad unexpected problems revolving around money, drugs, and even sex.

All of the fiduciary's actions should be performed for the advantage of the beneficiary. The duties of a fiduciary spelled out by laws include loyalty and reasonable care of the assets within custody. Caregivers and caretakers must not use the assets of

the elderly person for their own gain. This is more than a moral responsibility; this is a legal obligation.

Here is a job description for fiduciary: Caregivers need to know about financial matters; have good communication skills and interpersonal skills; possess a great deal of patience and stamina and an understanding of human relations; and acquire a knowledge of health care terms, medical conditions, and medications, because they often need to work through family situations, crises, and life-threatening events related to their elderly person's care, which may also involve dealing with law enforcement officers and attorneys.

According to legal dictionaries, the word “fiduciary” comes from the Latin word *fiducia*, meaning “trust”—a person who has the obligation and power to act for another (often called the beneficiary) under circumstances which require good faith, total trust, and honesty. This trusted care does not come without cost to the caregivers.

Caregiving is not only hard work, it also comes with several financial burdens. These include disruptions to employment, extra costs while caregiving, and even a toll on the health of the caregiver. Here is a look at the three main challenges:

- **Disruptions to Your Employment.** Caregiving takes time. Caregivers often have to use work time to handle caregiving responsibilities. Typically, there will be emergency interruptions that must be dealt with that interfere with work duties. An unexpected fall may require a fast trip to the emergency room. Caregivers naturally find they have to use up their vacation time and sick benefits to provide eldercare. There are other sacrifices, such as giving up advancement opportunities at work and the possible loss of fringe benefits.
- **Tapping into Your Purse and Wallet.** Caregiving takes money. Eldercare is never cheap. Caregivers use more gas and other resources to care for their loved one. There are also costs for delegating tasks a person would have otherwise done for themselves if they had the time, such as lawn care. Additionally, there is the loss of wages or business income and the costs to replace lost fringe benefits.
- **Tolls on Your Health.** Caregiving takes its toll. Not all the costs are financial. Caregiving means increased stress and burnout. The elderly with brain-related issues may exhibit agitation, angry outbursts, or inappropriate behaviors, which might include verbal or physical abuse. Dealing with that

can result in spending more on stress relief, such as eating out more often and consuming more alcohol. This gets compounded by the loss of time off and vacation time. There also is the stress of constantly being on vigil (as the Navy would put it, “constantly standing your battle stations”). Often there is increased medical costs for the caregiver from stress related illnesses.

An additional stressor is the proper management of the costs for the care recipient. These include the medical costs not paid for by insurance or Medicare, the legal costs for such things as power of attorney and living trust documents, and the costs of formal caregivers while the caregiver in charge is at work or sleeping. Of course, one of the largest costs for the recipient is the cost of care settings. These include adult day care, nursing homes, and assisted living facilities.

MYTHS ABOUT THE ELDERLY

When it comes to being forced into the role of caregiver, the situation usually begins with a tremendous lack of knowledge. Being unprepared for the role of caregiver is not unusual; people don't know what they don't know. The common hope is that there is an easy solution that others have found. Sadly, this is not the case.

This book aims to quickly bring caregivers up to speed on a number of issues. This Shady Acres eldercare myth needs to be debunked like a lot of other myths about eldercare. Here is a quick sampling of perception and reality.

- **MYTH: Sickly.** Forget the perception that all old people are aging, bedridden seniors who wind up in a nursing home. The elderly are living longer and healthier lives. Studies at Boston Medical Center found that in over 40 percent of seniors who lived to be 100, sickness related to old age did not occur until they were eighty. Census data from 2006 revealed that only 7.4 percent of Americans over the age of seventy-five live in nursing homes.
- **MYTH: Serene.** Many are familiar with the term “the golden years.” referring to retirement. Actually, for many these are stressful times. In fact, suicide rates are higher for people over sixty-five than for younger people.
- **MYTH: Senile.** No, not all of the elderly go senile, which actually has come to mean a disease of dementia. In fact, only 8 percent of those over sixty-five will develop some form of dementia, including Alzheimer’s Disease.

- **MYTH: Sexless.** Research has found that sexual activity and enjoyment do not decrease with age. As one blogger on certifiedcare.org noted, “some adult caregivers are shocked when a seventy-five-year-old parent who’s lost a spouse starts serious dating.”
- **MYTH: Surly.** A commonly-held belief is that all old people are surly, irritable, and cranky. As people age, there are more aches, hassles, and challenges that would frustrate anyone. But generally, if people got along well with others when they were young, they will do the same when old. But if someone was difficult to get along with when they were young, they will remain difficult to get along with as they age.
- **MYTH: Strapped.** According to the U.S. Census Bureau, only around 9 percent of Americans sixty-five or older have incomes and assets that fall under the poverty line. Actually, older adults tend to be better about saving money and being careful about their spending. The problems develop when others, like their own children, get control of the money.

But it would be foolhardy to believe that all of the elderly will be able to take care of themselves until

they die. Most will need the help of caregivers and caretakers, be that a child or a spouse. That is probably why you are reading this book.

WHAT ABOUT NONMEDICAL HOME CARE OR CONTINUING CARE RETIREMENT COMMUNITIES?

Some elderly people are hellbent on staying home. This has spawned an entire nonmedical home care industry that is quick to sing the praises of aging in place and not leaving the homestead. Rarely, however, do they discuss the dark side.

If cost savings are the major reason for choosing nonmedical elderly home care, the forgotten expense is senior-proofing the home. Many existing homes are filled with built-in booby traps that become increasingly difficult to navigate with age. Stairs can be a major problem, and while it is possible to install electric chairs on staircases, they are expensive.

There is another problem with the nonmedical part of the caregiving. What happens if Mom keeps pooping her pants? The nonmedical part means in some states the person who comes by is not allowed to touch the elderly person—a fact many caregivers and caretakers

do not know until the person is hired and on the job. Also, they definitely cannot give medications.

Some ask: what about continuing-care retirement communities that offer a variety of living options—from independent living to assisted living to nursing care—all within one community? Then Mom or Dad can stay in one place but move from one type of residence to another as their health care needs change.

Sounds good on paper, but they are pricey. Entrance fees for these communities, of which there are some 2,000 nationwide, can run anywhere from \$100,000 to \$1 million, and monthly fees can range from \$3,000 to \$5,000, if not more.

Many elderly people overlook the financial risks they take on when signing a contract to move into a continuing care retirement communities. In most states, this is an unregulated industry, and people could lose their entire investment should the community go bankrupt.

THE ANSWER MUST BE ASSISTED LIVING

Ah, some say, Shady Acres does exist: it is called the assisted-living home. They will take care of all the

eldercare problems, including those messy drawers. Wrong, wrong, wrong.

Equating assisted-living facilities to an idyllic Shady Acres is a gross miscalculation. Since they came upon the scene in 1981, when assisted-living facilities made their debut as a midpoint between home care and a nursing home, they've steadily grown in popularity. However, these are not charitable nonprofit institutions out to serve the public good; eight out of ten are for-profit, as are about 68 percent of nursing homes. More money at stake can mean more problems.

To be fair, there is no legal definition of assisted-living; this is purely a marketing term. While we know what a nursing home is by law, we cannot be so sure when a facility advertises itself as featuring assisted-living quarters. In fact, we have a much clearer picture of what a hotel is than an assisted-living facility. While I do not have anything against assisted-living facilities making money, people need to know they are not the perfect solution for all. Like any for-profit business, assisted-living facilities are out to make money for their investors. The rising cost of assisted living means that many families need to consider aging in place, home care, and multi-generational housing instead. In

addition, just trusting that an assisted-care facility will provide top-notch care is naïve. It is not unusual for an assisted-living facility to begin charging extra fees when a resident's health declines and he needs help with getting dressed, taking medication, or bathing.

On top of that, if the assisted-living facility does not like you, you are out. Residents are asked to leave when they are disagreeable, their health care needs change, or they cannot afford the costs and need to rely on Medicaid. Unlike nursing homes, assisted-living facilities don't have an industrywide process for appealing such decisions when a resident gets a boot out the door.

“We're dealing with an interesting situation,” one anonymous caregiver shared about an eldercare eviction. “Our grandpa is in his 80s but he's quite the escape artist and has been escaping care centers for awhile. One time he hacked a keypad and hot-wired a car. He got about twenty-four miles away before we could catch him. Anyway, I understand the ‘if we don't like you, you're out’ situation. We've constantly had to deal with that with my grandpa the way he is.”

So the time has come to put the Shady Acres fantasy to rest once and for all and face reality. The reality is that the elderly and their caregivers and caretakers

do not face one solitary problem such as how to find the right care facility. In fact, the problems are six-fold: something I have nicknamed the Six-Headed Eldercare Beast. This is definitely a beast you do not want to face unarmed and uninformed.

ENTER THE SIX-HEADED ELDERCARE BEAST

The dirty little secret of eldercare in America is that it is not just one problem for caregivers and caretakers; instead, it is an interrelated set of a half-dozen problems. All of the problems can come at you at once, which gave rise to the metaphor of a six-headed monster.

When I think of the Six-Headed Eldercare Beast, I am picturing something akin to the multi-headed serpentine monster called the Hydra that Hercules did battle with in Greek mythology. From the murky waters of the swamps near a place called Lerna, the Hydra would rise up and terrorize the countryside. A monstrous serpent with many heads, the Hydra attacked Hercules with poisonous venom.

Like the Hydra of lore, eldercare challenges attack on several fronts. The Six-Headed Eldercare Beast battles caregivers and caretakers with money challenges,

medical challenges, psychological challenges, social challenges, environmental challenges, and legal challenges. Some are even a matter of life or death. Making a mistake in any of these six areas can have serious consequences. Part II of this book gives advice on avoiding the following kinds of eldercare mistakes:

- **Money Mistakes.** When it comes to protecting yourself against financial abuse, it's important that you trust your instincts. But there are also practical steps you can take to safeguard your money.
- **Medical Mistakes.** Health care can be an explosive issue that is a chief concern. There are several medical mistakes that can arise in long-term care. It is crucial to keep an eye out for these issues, because they are easy to overlook.
- **Psychological Mistakes.** Unfortunately, many older Americans are living increasingly isolated lives, leading to depression or a general decrease in quality of life. They may be suffering from their own personal neglect, or they may actually be suffering abuse from a neighbor, a family member, friends, or someone else they know.

- **Social Mistakes.** The social area takes into consideration the family (or the lack of family) and the distance the family may live away from the person who needs care. It also involves social situations that can cause clashes because of everyone having an opinion as to what the person's long-term-care needs may be.
- **Environmental Mistakes.** The environmental eldercare concern revolves around where the elderly person lives, or should live. This often creates considerable conflict within the person him- or herself and within the family. This is a need that evolves.
- **Legal Mistakes.** In navigating eldercare, few consider the legal aspects. There are many issues that can cause potential pitfalls if not properly documented and understood.

USE THIS BOOK AS YOUR CANDID GUIDE

The silver lining on the dark storm clouds of eldercare is that there are information and experts to help guide you. My purpose is not just to raise issues, shatter myths, and point out mistakes. This is not a scholarly textbook or sugar-coated collection of tips. What this

book promises caregivers and caretakers is straight talk on the subject.

Providing this information is my life's work. I am the owner and founder of Eldercare Advocates, a private geriatric care management and long-term-care consulting firm. My firm provides comprehensive assessments and planning of long-term-care needs of disabled adults and the frail elderly. Assessments are made across the medical, psychological, social, environmental, legal, and financial aspects of a person's life.

As a professional fiduciary, I work with seniors, disabled persons, and other individuals who can't manage their affairs on their own, assisting with everything from day-to-day financial issues to investment and estate management.

My career began in nursing homes and hospitals. After finishing paramedic training and a degree in nursing, I pursued an interest in how people could finance health care, and primarily acute care. I found out that chronic long-term care is where financial devastation generally occurs for many people, especially the retired.

As an eldercare advocate, it is my mission to educate all involved and provide vital information that is needed to make informed decisions. As the old adage states, “forewarned is forearmed.” Before I share some cautionary tales, let me share a confession or two about eldercare.