# ELDER CARE CATASTROPHE

# RITUALS OF ABUSE IN NURSING HOMES & WHAT YOU CAN DO ABOUT IT

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ROUTLEDGE

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We dedicate this book to all nursing home residents who have suffered from the unanticipated consequences of bureaucracy and all of the nursing home employees who have to juggle work tasks and emotional well-being while trapped in the iron cage.

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# Contents

# Preface

We met ten years ago on the campus of Oklahoma State University. One of us was teaching a graduate-level social theory course. The other was a wide-eyed student taking the course in one of his first years of graduate school after deciding not to become a nursing home administrator following some time working at a facility in northeast Arkansas. In the course, one topic covered was bureaucracy—the organizational type sociologist Max Weber argued leads to the objectification of people with its focus on staff separation, rules, documentation, and efficiency. Outside of class, we discussed the bureaucratic dynamics that apply to nursing home life and our own experiences with loved ones and long-term care. Those conversations led to a series of research projects. Nine years later, we decided to write a book called *Elder Care Catastrophe* based on our academic investigations and personal experiences with nursing homes.

Nursing homes have been around for many decades. While family and friends still provide a majority of elder care, nursing homes remain a relevant component of the long-term care industry. Although alternatives to nursing homes currently exist, including assisted living and home health services, many elderly

people who cannot age in place for various reasons still end up in nursing homes. That makes problems surrounding nursing home care highly relevant, especially with the baby boom generation entering retirement age.

C. Wright Mills (1959) argued that it is essential for us to use our "sociological imaginations" to recognize that public issues help to explain much of our personal troubles. Unfortunately, we live in a time when people like to point the finger at individuals when explaining the consequences of social problems. The existence of nursing home neglect and abuse is no exception. We use the Mills perspective throughout this book to argue that bureaucratic ritualized practices facilitate much of the maltreatment occurring in nursing homes. The book starts with chapters reviewing nursing home neglect and abuse, the growth of bureaucracy, the history of nursing homes, and themes of bureaucracy relating to nursing home maltreatment. It then provides a systematic categorization of different forms of nursing home mistreatment, including chapters on emotional neglect, physical maltreatment, and verbal abuse. In a subsequent chapter, we detail what we call the CARE model—a systematic set of recommendations to lessen aspects of resident neglect and abuse in nursing homes. The book concludes with a chapter discussing how nursing home neglect and abuse is part of a larger bureaucratic catastrophe.

We believe the book can be beneficial to a variety of people, including academicians, whether they are interested in gerontology, organizational analysis, or sociology. We also think policy makers, especially those with an interest in political issues on long-term care, can increase their understanding of nursing home issues by reading this book. We hope people who work in nursing homes, from front-line staff to top administrators, will benefit from the bureaucratic awareness provided by *Elder Care Catastrophe*. Finally, we anticipate that potential residents, current residents, and family

members of residents will gain considerable insights on nursing homes by reading the book and reviewing the appendices, which include recommendations on nursing home selection.

In closing, we would like to thank all those people who contributed information for this book. This includes a variety of nursing home residents and their family members, as well as people working in nursing homes. We also thank Cole Smith and Ashley Lumpkin for the information we used that came from their interviews. Kristen Ulsperger did a great deal of reading and editing for this project, and she deserves recognition for it. Finally, we would like to acknowledge the help of Bernard Phillips, who spearheaded the formation of the Sociological Imagination Group. He provided us with a great deal of extremely valuable advice and has from the very start strongly supported and encouraged our writing of this work. We would also like to thank Dean Birkenkamp, Paradigm's publisher, who has also been particularly helpful and supportive of this project. We are truly indebted to all of these people.

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# Chapter 1
# Just Wanting to Die

> In a hospital they throw you out into the street before you are half cured, but in a nursing home they don't let you out till you are dead.
>
> George Bernard Shaw

A nursing home bus crushed Mary C. Knight. With her body behind the left rear tire, the driver shifted into reverse. According to the driver, something felt like it was keeping her from backing up. She was right. It was Mary's left arm and back. The Benton, AR, nursing home resident had just arrived at a vocational program affiliated with her long-term care facility, Arkansas Health Center, when the incident took place. Somehow, staff lost track of where she was after the bus unloaded. According to Arkansas' Office of Long Term Care, someone heard Mary say the day before that she wanted to die (Managed Care Weekly 2004; Smith 2005).

The courts ordered the elderly Knight to the supervision of Arkansas Health Center after finding her incapable of living in mainstream society. Psychiatrists diagnosed her with dementia, bipolar disorder, and alcohol-dependence issues. Based on these issues, it seems Mary's death might have been a suicide, a position held by

the Arkansas Health Center. However, Mary's ex-husband thinks differently. He decided to sue the facility, the state of Arkansas, and the vocational program operating under the nursing home's trust. His attorney believes litigation is necessary because, "Anyone who suggests that this lady was distraught or depressed or suicidal overlooks the fact that she was also committed involuntarily to that institution." He goes on, "One of the things that you have to do when the state has custody of someone who's incompetent and insane is they've got to take care of them" (Smith 2005).

Mary's death was another in a long line of mysterious deaths at Arkansas Health Center. In a period of one year, five deaths associated with employee mistakes occurred at the institution. Other questionable events cited by nursing home investigators included staff ritualistically neglecting privacy by failing to knock on resident doors when entering and allowing resident catheter tubes to drag the floor. Again, those were the cited issues. A couple of years before her death, Mary was involved in an undocumented instance involving poor employee supervision. She left a work therapy building on the grounds and came up missing. Someone eventually found her lying on the ground with her pants pulled down. A male resident was allegedly kneeling over her with his penis exposed (Managed Care Weekly 2004).

Unfortunately, incidents such as Mary's are not rare. They are just a couple of examples of the many acts of neglect and abuse that happen in U.S. nursing homes every year. While elder abuse is common in nursing homes, we do not think it is always something employees want to happen. We believe that in a nursing home's daily grind, which includes large numbers of rules, regulations, and paperwork, goals for providing compassionate care get lost. In turn, many forms of neglect and abuse occur. Family members, researchers, and policy makers need to start seriously turning their attention to this social problem. This chapter starts building your

understanding of America's elder care catastrophe by discussing elderly population growth, the long-term-care continuum, and the growth of maltreatment in nursing homes. It concludes with an outline briefly stating the purpose of each remaining chapter in the book.

## The Age Wave

To understand the relevance of nursing home maltreatment, it is important to know that the United States, a once young country, is getting old. Dychtwald refers to this population shift as the "age wave" (1999:57). The average person in the United States now has more living parents than children and an American woman spends more time caring for her parents than for her own kids (Riekse and Holstege 1996), all because the population aged 65 and older is growing at its most rapid rate ever.

Although it seems strange now, in colonial times, most of the American population was under the age of 16. Many did not make it to old age. Even up until 1900, life expectancy at birth in the United States was around 50 years (Bova and Noble 2007). Two factors kept the population young: elevated fertility rates and high rates of mortality. However, both of these factors flipped during the twentieth century, and a movement occurred involving the desire to control aging processes. The result of these factors was a demographic quake: The winds of aging shifted and the age wave emerged.

### Fertility-Rate Shifts

Fertility is the ability to produce children. At the dawn of the twentieth century, the fertility rate was high, with an average of seven births per woman. By the end of the century, it dropped to

two births per woman (U.S. Bureau of the Census 1993). People started having fewer children for a variety of reasons. There were more opportunities for women outside of the home and having a multitude of children to care for at home limited those opportunities. Medical advances such as the birth control pill provided women with reliable options for pregnancy prevention (Quadagno 2008). However, the biggest influence on fertility and the age wave involved baby boomers. The shift from a birthing to an aging culture gained momentum after World War II. Millions of service personnel returned from overseas. These soldiers met young women in waiting and the result was an explosion in births. Between 1946 and 1964, the number of births was 70 percent greater than in the previous two decades (U.S. Bureau of the Census 1993).

The baby boom put a large strain on institutions. When boomers reached school age, there was a shortage of schools for them. Hospitals could not meet increased demands for child health care. Dwellings such as apartments did not have enough bedrooms for kids. Baby food ran low, diapers were scarce, and stores could not keep enough toys stocked. When birth rates declined, people realized that the baby boom generation would be a concern at every stage of life. When they reached early adulthood, college enrollments swelled. In the 1970s, they purchased homes and the increased demand prompted a rise in prices. The average cost of a new home went from $26,000 to about $47,000. The power of baby boomers continues to influence American life. Some people think that boomers will sway most political and consumer decisions made in this century (Dychtwald 1999; Quadagno 2008; Siegel 1993).

## Mortality Transitions

Mortality involves likelihood of death. In 1900, the chance of dying young was high and the odds of living to old age were low.

Around 20 percent of white children and 30 percent of nonwhite children died before turning five. About 60 percent of white females and 30 percent of nonwhite females reached the age of 60. Only half of white males and nearly 30 percent of nonwhite males could expect to live to 60. Now, infants in the United States have a better chance than ever to survive to old age. Whites continue to have an advantage in life expectancy over nonwhites. However, the gap is shrinking. Reaching the age of 60 now is possible for around 90 percent of white males and females. Slightly more than 90 percent of nonwhite females and 80 percent of nonwhite males reach 60 (Serow, Sly, and Wrigley 1990; U.S. Bureau of the Census 1993).

Big declines in death rates occurred in the 1940s and 1970s. During the 1940s, medical technology led to gains against infant and maternal mortality. In other words, more children lived past birth and more mothers made it through the birthing process. In the 1970s, death rates from heart disease declined because of prevention and treatment methods. People were smoking less than before, and new prescription drugs controlled high blood pressure. People were healthier and segments of the population expanded. This included the elderly. In fact, the fastest growing population group is now people 85 years old and older (Quadagno 2008; Treas 1995).

In 1900, 122,000 people aged 85 and older lived in the United States. At the turn of the millennium, that number increased to more than 3 million, and estimates indicate that it will reach nearly 6.5 million by 2020. The number of people over the age of 100 is also increasing at a rapid rate. In 1879, the odds of living to 100 were only 400 to 1. In 1980, the odds increased to 81 to 1. Now, there are more than 50,000 people aged 100 years and older in the United States. With advancing technology, we expect those numbers to continue to rise. The United States will soon have the largest elderly population in the world (Bova and Noble 2007; Riekse and Holstege 1996; Spencer, Goldstein, and Taeuber 1987).

## Controlling Aging

We are on the verge of touching the outer limits of the human life span thanks to what we identify as the age control movement. Five breakthroughs continue to push this late-twentieth-century movement. They include super-nutrition, hormone replacement, gene therapy, bionics, and organ cloning.

Super-nutrition involves a diet rich in nutrients but low in calories. A correlation between specific food ingredients and disease prevention indicates that vitamins C and E, beta-carotene, and selenium can reinforce the immune system and prevent heart disease and even cancer (Dychtwald 1999). Hormone replacement involves supplying hormones for which a person is deficient. Regelson (1996) indicates that hormones injected into the body can slow and even stop the aging process. People use estrogen, testosterone, and human growth hormone as hormone supplements. Gene therapy focuses on changing cellular clocks found at the tips of chromosomes, which scientists call telomeres (Lewis 1998). Cells rejuvenate at astronomical rates when they are genetically changed. When dividing, the potential to increase the life span of aging cells exists. This allows an increase in human life span (Bova and Noble 2007). Bionics involves the use of artificial limbs and organs. Cloning involves the creation of human tissue in a laboratory setting and has the ability to benefit elderly people with brain diseases or cancer patients needing healthy cells (Dychtwald 1999).

With these technologies, by the end of the twentieth century life expectancy reached 76 years for males and 83 for females. The average American who lives to age 50 can expect to live even longer than that (Bova and Noble 2007). Regardless of medical breakthroughs, not all people reaching old age will be able to care for themselves. We cannot yet take a human brain and transplant it into a mechanical body in order to function beyond our physical

limitations as humans. With the current pace of technology, we wonder if that possibility is far off. Regardless, many of the elderly still require intensive supervision due to cognitive impairment and severe health problems. Coupled with the age wave, we believe this will prompt a rise in the demand for elderly services all along the long-term-care continuum (Ulsperger and Ulsperger 2002).

## The Long-Term-Care Continuum

Long-term care involves a range of health supervision, personal care, and social services given over a lengthy amount of time for people who cannot care for themselves. Informal long-term care, which friends and relatives give, is the most common form (Montgomery 1992). The common belief that Americans focus on youth and autonomy while disregarding the needs of the aged is a myth. In the United States, young family members still provide a majority of care for their elderly loved ones (Brody 1984, 1990).

American women provide most informal long-term care for the elderly. Indeed, more than 70 percent of long-term care providers are female family members (Stone, Cafferata, and Sangl 1987). These women pay a high emotional price because women have a hard time distancing themselves from caregiving (Zarit, Todd, and Zarit 1986). Family obligations do lead to care by younger generations, but we think the use of formal long-term care will increase because family size is shrinking and more women are spending time in the labor market (Cicirelli 1990).

### Formal Long-Term Care

For people who do not have the capability to care for an aged loved one, a nursing home does not have to be the first option. A variety

of alternatives exists, including home care, adult day care, respite care, and assisted living. If a nursing home does not seem right for your situation, any of these programs might fit your level of need.

Home care refers to in-home health and supportive services. This includes professional, paraprofessional, and long-term care in a recipient's home. Home care is hard to define because it includes a wide range of services. For example, it includes physician and nurse visits as well as house-cleaning services. The use of home-based services is not widespread. At the end of the twentieth century, only three percent of the elderly in the United States reported using a visiting nurse and two percent used home health services and home-delivered meals (Montgomery 1992; Stone 1986). However, the use of such services is increasing (Marrelli and Whittier 2008).

Adult day care involves community programs that provide services to older people. They usually run in daytime hours. Adult day-care facilities vary in terms of emphasis, but two primary models exist. The first is the health rehabilitative model, which offers medical, nursing, and therapy services. The second type is the social psychological model, which involves people recovering from illness and those who typically have dementia. Adult day cares are located in a variety of settings. Charging by the hour and by the day, they operate in churches, senior centers, and hospitals (Giacalone 2001; Montgomery 1992). More than 1,000 exist in the United States averaging a daily enrollment of 24 people (Conrad, Hanrahan, and Hughes 1990; Richardson, Dabelko, and Gregoire 2008).

Respite care involves planned relief. It allows people to drop off elder family members at a facility. With these services, you can essentially pay for hourly temporary care to get a break from the exhaustion that can occur when taking care of a loved one. Family caregivers often show declines in physical and mental health due to chronic fatigue, isolation, and financial stress. Through respite care services, caregivers can take time out to pursue personal

interests and relaxation (Mace and Rabins 2006; Scharlach and Frenzel 1986).

Assisted-living facilities are for non-impaired elders needing help with some activities of daily living such as food preparation, bathing, and medications. People in these facilities do not need 24-hour care. They receive meals in a common dining room, but have separate lodging and housekeeping services. Assisted-living facilities have a small staff of at least one nurse, a social worker, and a case manager. They contract health care services to external agencies, which keeps costs low. Often, people in these facilities pay with private funds (Giacalone 2001; Seipke 2008). If you or your aged loved one is not financially secure enough to afford assisted living, or if your elderly loved one needs a higher level of supervision, you might have to consider nursing home options.

## The Nursing Home as Long-Term Care

Nursing homes provide a majority of formal long-term care. They treat patients with chronic illnesses. Although they provide less intensive care than general hospitals, they do have trained nursing staff. Medicare and Medicaid certify nursing homes as eligible for reimbursement based on the type of care provided. More than 95 percent of nursing homes receive government reimbursements. By doing so, they subject themselves to inspections carried out by state officials. In addition to providing elders who cannot care for themselves a place to live, nursing homes provide help with what people in the industry call activities of daily living, or ADLs. This includes assistance with anything from dressing to bathing. Nearly 50 percent of people who live in nursing homes have dementia. In fact, more facilities than ever now exclusively serve cognitively impaired populations or have at least one designated area that focuses on them. For example, many nursing homes have Alzheimer's wings

(Carlson and Hsiao 2006; Kahana and Brittis 1992). The average cost for a private room in a nursing home is currently $75,190 per year. A shared room with a partition between the beds averages $66,795 per year (MetLife 2006).

Through the 1980s, levels of care at nursing homes ranged from certified skilled nursing facilities (SNFs) to intermediate care facilities (ICFs). SNFs provided supervision 24 hours per day for residents under the care of a registered nurse. Like assisted living facilities, ICFs provided lower levels of care (Sirrocco 1989). After the Omnibus Budget Reconciliation Act of 1987, also known as the Nursing Home Reform Act, the distinction between SNFs and ICFs blurred. Most agencies now classify all of these institutions as nursing facilities (Carlson and Hsiao 2006; Richardson 1990). Regardless, do not get perplexed over names. As some analysts point out, when facilities do not want people to recognize them as "nursing homes," they will actively promote other names to avoid any stigma associated with the nursing home label. This can be anything from health care facility to rehabilitation center (for more on this phenomenon see Ulsperger and Paul 2002). To avoid confusion, throughout this book, we simply use the term nursing home.

### *Facility and Resident Numbers*

The number of nursing homes in the United States peaked in 1985, with slightly more than 19,000 facilities. Then new ways of care previously mentioned, such as home health care and assisted living, started replacing services provided by nursing homes and the number of facilities declined. In addition, disability rates for the elderly lowered the number of aged people entering nursing homes. This trend did not last long. Reports indicate that the number of nursing homes was on the rise again in the 1990s. In 1991, the number of nursing homes in the United States neared 16,000

facilities. The Centers for Disease Control, which monitors nursing home health statistics, indicates the number is currently 16,100. Moreover, the presence of the "old-old," people 85 and older, in society is starting to increase disability prevalence among the elderly again, possibly setting the stage for another sharp increase in the number of nursing homes in the United States (Lakdawalla and Philipson 2002; Gabrel 2000; National Center for Health Statistics 2006; Strahan 1997).

Regardless of national trends, nursing homes themselves are getting larger. Consider the average number of beds per facility. It increased from 75 in the early 1970s, to 107 in 1997. As of 2004, 40 percent of nursing homes had 100 beds or more. Although there may be fewer nursing homes than at the industry's peak, the ones that exist are bigger than ever. The actual number of residents per facility also increased over the past few decades, receding a little only recently. In the early 1970s, a little more than one million people lived in nursing homes. By 1997, the number was 1,608,700, dipping slightly to 1,492,200 by 2004 (National Center for Health Statistics 1988, 2000, 2006).

Many people assume that most of the elderly live in nursing homes. We want to emphasize that this is a fallacy. The true number of the elderly living in nursing homes is around 4 percent. However, this figure is a little misleading. Nearly 25 percent of people over the age of 65 will spend time in a nursing home, so the likelihood of an older person's admission is high. The number, 4 percent, is also cross-sectional. It does not take into account movement in and out of nursing homes (Hooyman and Kiyak 1996; Pandya 2001). We can point out that the most common reasons for nursing home admission are circulatory disease and cognitive impairment. Problems related to cardiovascular issues, such as a stroke and its related effects, comprise 17 percent of new admissions relating to circulatory disease. The main cognitive problem relating to admission is

symptoms of Alzheimer's disease (Sahyoun et al. 2001). Keep in mind, if you ever have an elderly loved one in a nursing home, the facility may not exclusively cater to the aged. Younger people with serious health problems relating to ADLs may live in the facility as well. Nonetheless, the average age of admission for elderly residents into a nursing home is 83, up from 81 just a few years ago. Approximately 88 percent of nursing home residents are elderly, with 50 percent over the age of 85. Close to 90 percent of residents are white and just over 70 percent are females (Giacalone 2001; Houser 2007; National Center for Health Statistics 2000; Sahyoun et al. 2001).

### *Ownership Trends*

In relation to ownership, in 1986, only ten publicly held nursing home chains existed. These for-profit businesses owned and leased 170,000 beds. Though the number of nursing homes dipped for a period, the number of nursing home chains has grown. The current top ten chains account for nearly 300,000 of the nursing home beds in the United States (Giacalone 2001). In the early 1990s, the largest chain owned slightly more than 1,000 facilities with more than 100,000 beds in its possession (Forrest, Forrest, and Forrest 1993). As of 2000, it had 67,000 employees and sales reports of $116.8 million in revenue. That chain, Beverly Enterprises Incorporated, was sold to Fillmore Capital Partners for $1.8 billion in 2005 (Burling 2007; Dun and Bradstreet 2000). Since that time, buyouts and mergers have been the rage in the industry. In May 2007, Genesis, a Pennsylvania-based long-term-care corporation, accepted a merger proposal from Formation Capital and JER Partners for $1.4 billion, beating the best offer by Fillmore. In December 2007, Carlyle Group closed a $6.3 billion buyout of nursing home operator Manor Care. For-profit nursing homes,

which include facilities operated by the big chains just mentioned, comprise around 60 percent of the market, with nonprofit facilities, including government homes, accounting for the rest (Meyer 2008; National Center for Health Statistics 2006).

Some sociologists believe the increased use of for-profit care, such as that in the nursing home industry, is creating a crisis with the logic that paid care leads to poor care (see for example Glenn 2000). The basic argument is that cutting corners to increase profits is costing residents quality health care and safety. However, as we argue in this book, it is possible that the focus on bureaucracy in nursing homes, regardless of ownership status, carries just as much responsibility for promoting maltreatment.

## Maltreatment in Nursing Homes

Maltreatment in nursing homes involves any deviation from predicted standards for high quality care, such as physical violence, verbal aggression, and various forms of neglect (for further elaboration see Pillemer and Moore 1990). Concern over nursing home maltreatment existed for years only to become a national issue in the 1960s (Horton et al. 1997). It was then that tales of nursing home abuse started appearing in newspapers and books (see Townsend 1971; Mendelson 1974; Vladeck 1980). Government officials sensed the rise in negative sentiments and started a series of investigations (Buhler-Wilkerson 2003).

In 1986, Congress requested that the Institute of Medicine draft a report on the quality of care in nursing homes. The report confirmed academic warnings and print media stories of problems. A follow-up study conducted by the U.S. General Accounting Office found that more than one-third of nursing homes had bad care. In reaction, Congress signed the aforementioned Omnibus