Executive Summary

The pages of this book demonstrate the impact of neglect and abuse in long-term care facilities — not in statistics but in the tragic, real experiences of such productive members of society as homemakers and teachers, engineers and nurses.

Those depicted endured severe, unnecessary suffering at the most vulnerable time of their lives. The faces you see here could be those of your mother, father, grandmother, grandfather, sister, brother, or one day, yourself.

All but one of them were plaintiffs in lawsuits. As a result of poor care and weak enforcement of public laws regulating long-term care facilities, they and others like them — residents and their families — turned to the civil justice system as a last resort.

Most lawsuits against long-term care facilities are brought for multiple, serious omissions of care that cause life-threatening pressure sores, permanently contracted muscles, infections, broken bones, malnutrition, or dehydration. In spite of decades of congressional investigations and hearings showing egregious deficiencies in long-term care and poor enforcement of public regulations, Congress is considering legislation that, in practice, would prevent residents and their families from exercising their constitutional right to bring civil lawsuits against facilities that cause them irreparable harm or death. Proposed medical malpractice legislation, called “tort reform” by its proponents, would place severe caps on non-economic damages and would limit, if not end, residents’ ability to be compensated in the courts when the regulatory system fails them.

The families of those profiled in this book have given us permission to tell their stories because, as one victim’s daughter told us, she wants her mother’s experience to make a difference for others.

The victims’ experiences do not reflect those of all long-term care residents, nor do they negate the dedication and compassion of most workers in long-term care. Collectively, however, they tell the story of too many individuals who are ill-treated, ignored, or abused and for whom tort reform would mean losing a final opportunity to obtain recognition of the harm that was done to them and compensation from those who denied them compassion, dignity, and care.

Introduction

More than 2.5 million American elders and disabled adults live in nursing homes, assisted living facilities, and other board and care settings because they require around-the-clock nursing care and/or assistance. Some of these vulnerable adults suffer from neglect and abuse that can only be described as horrific. For them, and for their families, courts are the last resort and civil lawsuits are pleas for those responsible and our society to recognize their plight and keep others from suffering needlessly.

The purpose of this book is to improve understanding of why our society must preserve the right of long-term care residents, many of whom are in the last months or years of their lives, to seek justice. Their stories paint a heartrending picture of failure. Although several years have elapsed since the events in some of these cases occurred, each unfortunately illustrates the types of neglect and abuse that have prevailed in the long-term care industry for decades and continue today.
Neglect and Abuse
Despite federal and state regulation, regardless of the vigilance of dedicated health care workers and consumer advocates, and even with repeated media exposes and congressional hearings to bring conditions to light and provide solutions to the problems, neglect and abuse in long-term care facilities remain widespread.

Why do neglect and abuse persist? The reasons are complex, but the overwhelming reason is a chronic lack of enough well-trained and well-supervised nursing staff to provide necessary care. A 2001 federal study, based on research by leading experts in long-term care, documented that more than half of all nursing homes do not employ enough nursing staff to avoid harm to residents, and more than nine out of ten do not employ enough nurses and nursing assistants to provide good care. Ninety percent of care in nursing homes is given by nurse aides who struggle to do their jobs with little training, low pay, few benefits, minimal professional supervision, and limited resources. In 2002, annual turnover rates among nursing assistants exceeded 80 percent in 19 states, and exceeded 100 percent in 10 states.

Training and supervision of nursing home staff are often inadequate. A 2005 analysis of nursing home staffing data shows that the proportion of care provided by registered nurses is declining in spite of increases in Medicare funding earmarked for nursing. Moreover, the U.S. Department of Health and Human Services’ Office of Inspector General found that only 38 percent of medical directors visit their nursing homes more than once a week.

Neglect Becomes Abuse
Repeated lack of basic care or failure to provide enough competent, well-screened employees transforms neglect into abuse. When residents are not repositioned often enough to prevent painful pressure sores from forming and worsening, neglect becomes abuse. In severe cases, which you will see in this book, pressure sores multiply and deepen until the bone is exposed; the resident may die from infection. When residents are allowed to remain in one position so long that their muscles contract, permanent, painful disability—called contractures—occurs. When residents with dementia are poorly supervised and wander from the facility, they may fall and break bones or die from exposure.

Neglect becomes abuse when facilities hire workers without doing criminal background checks and residents are beaten or raped by convicted felons. Malnutrition and dehydration (by some estimates affecting up to 85 percent of all residents nationwide) occur because the residents are not assisted with eating or provided liquids on a regular basis.

Neglect becomes abuse when workers, who are struggling with heavy workloads, low salaries, and inadequate benefits, are not adequately trained or supervised.

While pain and suffering are incalculable, poor care carries financial cost as well. The cost of neglect in dollars has never been fully calculated but is certain to be immense. In some of the case profiles, we quantify hospital expenses that stemmed from neglect, but we could not capture other costs, such as those for antibiotics and other medications, surgical procedures, high-tech alternating-pressure relief beds used to treat advanced pressure sores, feeding tubes and catheters, and increased medical attention.

“Woefully Deficient Care” and Poor Enforcement
In 2004, long-term care ombudsmen investigated nearly 20,000 complaints related to abuse, gross neglect, and exploitation, and over 87,000 complaints about resident care. Also in 2004, regulatory agencies cited 26.2 percent of nursing homes nationwide for violations related to quality of care. Many of the facilities where neglect and
abuse occur are repeat poor performers with long histories of serious, identified problems that state regulators have allowed to continue year after year. In fact, the U.S. Government Accountability Office’s chief healthcare investigator told the Senate Finance Committee in 2003 that more than 300,000 elderly and disabled residents lived in chronically deficient nursing homes where they were “at risk of harm due to woefully deficient care.” He said residents suffered serious harm or died “when physicians’ orders were ignored, when residents were allowed to deteriorate due to malnutrition or dehydration without any intervention, or because bedsores went undiagnosed or . . . were not treated properly.”

Despite the widespread evidence of neglect and abuse in nursing homes, residents and their loved ones often have little recourse when serious harm, injury, or even death results. Government studies show that state regulatory agencies also suffer from understaffing and have high turnover rates among their surveyors, creating a shortage of experienced investigators. According to the Government Accountability Office (GAO) and the Office of Inspector General, state survey agencies frequently fail to cite facilities for harming residents, even when they find serious injuries; and when facilities are cited for deficiencies, fines or other sanctions often fail to reflect the seriousness of the violations.

A December 2005 report by the GAO is the latest government finding that state surveyors understate deficiencies that cause harm to residents or put them in immediate jeopardy. The study found that in five states that had a significant decline in serious deficiencies from 1999 to 2005, 18 percent of federal comparative surveys identified at least one serious deficiency missed by state surveyors, ranging from a low of 8 percent in Ohio to a high of 33 percent in Florida. The study also notes that numerous GAO reports from 1998 to 2004 document serious problems with nursing homes and the survey and enforcement system, including: a proportion of facilities that repeatedly cause actual harm to residents or place residents at risk of death or serious injury; understatement by surveyors of the extent of serious quality of care problems; long delays in investigations of complaints from residents, family members and staff alleging harm to residents; the failure of enforcement policies to ensure that deficiencies are addressed and remain corrected; and limited effectiveness of federal mechanisms for overseeing the state survey system. Another recent study by the Office of Inspector General found that fines were sporadically levied by state survey agencies and, when levied, often were minimal and collected late or not at all.

Investigations of assisted living facilities reveal that care and public oversight in other long-term care settings may be no better than in nursing homes. For example, The Washington Post reported in May 2004 that Virginia records showed that “about 4,400 residents have been victims of abuse, neglect or exploitation since 1995” in assisted living facilities and that 51 deaths might have been attributable to poor quality care. According to a 2005 report by the National Senior Citizens’ Law Center, only 19 states require hourly minimums for training of direct-care workers in assisted living and only 26 states require assisted living facilities to employ or contract with a nurse. Even in states that have this requirement, however, the nurse may not be required to be present at the facility but rather may review care plans or facility policies or be available only by phone.

**Capping Access to Civil Justice**

When a resident suffers egregious harm, and regulatory agencies do little or nothing to protect other residents or sanction the facility, some residents and family members turn to the courts to hold the facility accountable. All U.S. citizens have a fundamental right to seek justice before a jury when they are harmed. Yet, for those who live in long-term care facilities, this constitutional right is
now under attack in the U.S. Congress and many state legislatures.

In civil suits, the only way the court can compensate victims for injuries is by providing financial compensation for damages. Most civil cases involving persons who are in the workforce seek economic damages—reimbursement for out-of-pocket expenses like medical bills and lost wages or future earning potential. Non-economic damages are sometimes referred to as awards for “pain and suffering.” Unlike reimbursement for economic damages, non-economic damages are the only compensation a jury can award for the injury or wrongful death itself.

Since economic damages are rarely an option for long-term care residents because they do not have an earned income or earnings potential, non-economic damages are the only remedy available to compensate for painful injuries, permanent loss of limbs, loss of ability to function, and death.

A Harvard University researcher estimated in testimony before the Senate Special Committee on Aging in 2004 that 80 percent of all compensation in nursing home lawsuits is for non-economic damages. He testified that caps on noneconomic damages would block the ability of injured residents and their families to hold nursing homes accountable for their negligence.

Unfortunately, medical malpractice bills that have been introduced by federal lawmakers and enacted into law by some state legislatures include such caps. The caps would limit noneconomic damages to $250,000 in health care lawsuits, including those against nursing homes and assisted living facilities, while allowing unlimited economic damages for the able-bodied.

The effective result of this is that it would become financially impossible for attorneys to bring cases for victims who do not have economic damages.

The costs of bringing a case to trial — the costs incurred in discovery, obtaining the testimony of expert witnesses, depositions, and research — can easily reach into the tens or even hundreds of thousands of dollars. When the cost of bringing a case approaches the maximum compensation a jury can provide under an artificial and arbitrary cap, legitimate cases will be locked out of the courtroom.

In contrast, a jury would have no limit on the amount it could award a corporate executive who brought a tort case for loss of income.

Limiting non-economic damages devalues the lives of older Americans and increases vulnerability to abuse and neglect of every citizen in his or her final years. We are all at risk.

Losing the Deterrent Effect

In addition to making it almost impossible for residents to bring lawsuits against nursing homes or assisted living facilities, the limit on damages would remove the deterrent effect that monetary penalties have had on facility behavior, especially on facilities that are owned by multi-million dollar corporations.

Indeed, the president of a health care insurer in Colorado says lawsuits are having a positive effect. He told an insurance trade journal that the nursing home industry is “correcting itself,” conducting more background checks on workers and improving nurse staffing because more insurance carriers “will not take on the risk unless staffing ratios meet certain targets.”

Most victims of neglect or abuse and their families bring lawsuits to prevent those injuries and indignities from happening to other residents. In the words of one family member interviewed in the course of this project, “I didn’t want to file suit at first. I had never sued anyone before. But this should not have happened to my dad. I did it because changes had to be made.” Another family
member said, “I decided to pursue a lawsuit so that my mother’s story could be told and so her story could make a difference.” Eliminating meaningful access to civil justice removes one of the last effective remedies in the struggle to improve care in American nursing homes and assisted living facilities.

**The Story of Real People**

What follows is not a statistical sampling or an examination of the breadth or depth of neglect in long-term care facilities. Rather, it is the story of real people who were neglected and abused, with terrible, often fatal, consequences. In response to these experiences, these individuals, or their loved ones, decided to exercise their constitutional right to civil justice. We trust that their stories will help you understand why it is in the best interests of all Americans to defend long-term care facility residents’ access to civil justice.

We hope to bring home the fact that “reforms” in the tort system would bar elderly and disabled people in institutions from being adequately compensated for neglect and abuse. Finally, our goal is to someday eliminate the need for lawsuits by securing public policies that ensure adequate staffing, comprehensive person-directed care, and real quality of life in long-term care facilities.