

Daddy suffered in silence—Are you next?

A true story by B. Lou Guckian

One is too many, but an estimated 5 million older Americans are at alarmingly high risk for abuse and abusive neglect in elder-care institutions every year. Many more suffer at home.

Abuse is a small word that conjures up disturbing images of cruelty and violence. As my elderly father knew, abuse is more than just a word. It is a disease.

Like thirsty horses to water troughs, we as a society draw daily to TVs and websites to watch bloody cops-and-robbers shows or atrocities of foreign wars. The more we consume violent images the more anesthetized to violence we become. So it follows, we ignore the negligence and violence carried out against older people right before our eyes, in our homes and public healthcare institutions every day.



Most of us know the rhyme about the legendary Lizzie Borden, but how many of us have considered its truth? “Lizzie Borden took an axe and gave her mother 40 whacks. When she saw what she had done, she gave her father 41.” The reality is, in 1892 the middle-aged Massachusetts woman brutally murdered her elderly parents in a fit of family violence and got away with it.

A century later, with an untold number of crimes against the elderly, society still denies the gruesome truth of elder abuse.

The government has yet to fund a national study to conclusively quantify it, but state-based studies over the past few decades predict abuse will climb as the population ages at record rates: in 20 years, nearly 72 million Americans or 20 percent of the U.S. population will be 65 or older. Many of us will be among them. What then?

Borden’s jury refused to wrestle with the unimaginable—that a woman could kill her parents—and so, acquitted her of the heinous crime. But beware: History repeats itself. My father’s story is one case in point. While not about murder, it is about inhuman, abusive negligence.

Daddy's Story

I had just turned 50 the year Daddy turned 82.

From its place on the nightstand, my cell phone rang at 2 a.m. I knew who was calling before I answered. It came from the nursing home and made the scared six-year-old in me shudder.

“Hi, Daddy. Are you OK?” This time, he told me he had been lying for an hour in cold sheets wet with urine. He told how he had repeatedly pressed the red button clipped to his bed sheet to alert the nurses’ station but no one had come to help him use the bedside urinal.

Full of zip and lighthearted mischief before he got cancer, Daddy still suffered from incontinence caused by chemotherapy and radiation that had ended two months earlier. Thin as a skeleton and helpless as a newborn, he could barely raise his head off the pillow or punch numbers into the telephone—which he had quickly learned to cling to and sleep with.

I swallowed hard pushing down the sick swell in my throat and then asked him to hang up so I could call for help. I promised to phone him right back and did. Then I lingered on the line until someone arrived to help him. In a few minutes Daddy said, “They’re here now. Thank ya, Sugah. G’night.”

I think back on that night four years ago and remember the grace in his voice despite the circumstances. I know what heartbreak is, and I know my heart cannot hurt long enough or bad enough to ever come close to what he must have felt. What hurts the most is that he suffered in silence.

My father’s story actually began a few months earlier at Christmas when doctors diagnosed him with esophageal cancer and an equally grim prognosis. My mom, four siblings and I fell numb at the news. Doctors said daily doses of chemo and radiation or radical surgery could kill him, but he had a small chance of surviving if he could withstand the cure. If he did nothing he’d be dead in nine months.

Having no experience with a seriously sick older parent, I was ill-prepared for what lay ahead or the sordid end, which I would learn had little to do with my father’s illness or treatment but everything to do with discrimination against the old. In the end, Daddy said he would rather have died sooner than live through the “hell” he suffered as an old person in institutional “care.”

Early Warnings

The first evidence of neglect came four weeks into treatment at a prestigious cancer clinic in a nearby Texas city. The curative process commenced in mid-February 2005. By mid-March, my father had landed in the adjoining hospital an invalid and skeletal. He had lost 20 pounds, the result of incessant nausea, vomiting, and a charred throat that prevented eating or drinking. Doctors introduced intravenous hydration but neglected to insert a feeding tube, which resulted in malnutrition and accelerated the toxic impact of the chemo on Daddy’s major organs and bodily functions.

This was the first in a series of tragic missteps that prevented my father’s recovery and ultimately led to his untimely death. At the start, my dad entrusted doctors with the whole of himself—body, mind and soul—and plunged high-spirited and headlong into a supposed cure and rescue from too-soon a death. But neither he nor we could have known what would follow in its wake—a negligent medical and healthcare system that grossly disregards the elderly.

Once in a great while, we hear about flagrant disregard of old people. In September 2005, in the wake of Hurricane Katrina’s devastation to New Orleans, *New York Times* reporter David Rhode told of 154 people, mostly old, who died inside stifling hospitals and nursing homes when power failures knocked out air-conditioners—and rescue workers neglected to act to save the vulnerable old. Meanwhile, there were no reports of even a single lost life of hospital or nursing home employees. Rhode quoted Alice Hedt, executive director of the National Citizens’ Coalition for Nursing Home Reform, about the deaths: “The statement that you can judge a society by the way it treats elders and the vulnerable is a good way to look at our society. I hope this is going to be a wake-up call.”

Unless outrageous or extraordinary, most stories of abusive neglect go untold.

Following Daddy’s debilitating cancer treatment, my family and I found a “healthcare” system, rehabilitation centers and “nursing” homes steeped in ageism. Whenever I think the words “elder abuse and neglect,” they pop in my brain like bullets. We found ourselves face-to-face with widespread indifference observed in the attitudes and actions—or inaction—of medical practitioners, many of whom ignored our growing despair. We found ourselves confronted by something unconscionable and unstoppable.

Our family is not alone. More than three decades ago, U.S. Senator Charles Percy of Illinois asked Congress: “What is it that compels us to discard virtually anything that is old—including human beings—as if the signs of age mark one worthless?”⁴ In 2005, Senator Percy’s observations became very real for my family. We experienced ageism firsthand but did not know it by name. Similar to racism, which harbors hatred for people because of skin color, or sexism, which discriminates because of gender, ageism is prejudice against people because they are old.

Beginning with the cancer clinic, Daddy and his medical records got shuffled across six different healthcare facilities in two cities in only four months’ time. These places included hospitals, a long-term acute-care facility, rehabilitation centers, and ultimately the ramshackle nursing home from where his emergency phone calls came.

Meanwhile, my father wasted away like dust. We were of little help, shocked observers on the sidelines. Sometimes well-meaning families overcome with fear and stress unwittingly choose convenience over good care. In my father’s case, the nursing home was conveniently located near my mother’s house but clearly was not the best choice for him. Sometimes, family members cannot agree and

time to do homework is something few have to give. And sometimes, ignorance is as ubiquitous as it is harmful: Not one of us knew then about the over-drugging that followed Daddy place to place, as absent doctors prescribed drugs sight-unseen that held him prisoner in a bedridden body and mixed-up mind.

Ensuing Events

There was little time to plan. When Daddy first left the cancer clinic in Houston bound for our hometown in San Antonio, he made the three-hour trip by ambulance. It delivered him to an acute-care hospital we hurriedly found around midnight. When I visited him early that first morning, I found him lying in bed, disoriented—and the window of the street-level private room wide open to the outside. I found his false teeth exposed on a table, caked with hardened denture paste and other scum. Given Daddy’s vulnerable condition, I asked the admissions director about the open window. He smiled a superior smile and replied, “Some patients like fresh air.”

When I asked why my dad was not wearing his false teeth—knowing he never took them out except to clean and reinsert them—and why they were disgustingly dirty and smelled, the congenial admissions director kindly said his staff removes all elderly patients’ false teeth as a matter of policy and blamed the dirty dentures on the ambulance company—which when questioned denied the charge.

While I can believe there are good, caring places for the elderly and that some families have the luxury of time and the desire to plan ahead, I do not believe it is typical. It certainly was not so for our family, and we were caught off-guard.

My family found that arrogant unaccountability disguised as caring can run rampant where the elderly are concerned. Nursing homes often hire minimum-wage workers who lack the motivation or skills to care for our most vulnerable old.

We observed other unsettling things there. We saw nurses dropping pills on a highly trafficked floor, picking them up and putting them back into little plastic cups on the trays they carried, and then heading into patients’ rooms. We noticed that instead of addressing older patients by their names, nurses and aides used pet labels in patronizing tones much like adults do with babies. They spoke to us about Daddy in third person as if he were not present. And incessantly we asked where the doctor was.

Alarmed, we arranged for Daddy to relocate from the acute-care hospital to a remodeled rehab center in another part of town. But despite its freshly painted walls, spongy new carpet and spit-shined workers wearing pressed uniforms and name tags—and big friendly smiles—again we found the rehab center staff’s underlying attitude toward the elderly the same: impersonal, indifferent, dangerous.

We learned appearances are deceiving and the old are disgraced.

On one particular day, I found the door to Daddy’s “private” room standing wide open to a public hallway. Inside, an aide was lifting him, naked from head to toe, from bed. As she pulled him trembling

onto his feet, he suddenly lost control of his bowels, like an infant without a diaper. If I live forever I will never forget the shame and incomprehensibility of that moment on my father's face and the sorrowful words that escaped his mouth when his eyes met mine. It does me no good to swipe away the unwelcome, recurring memory from my mind; it is stuck there, returning, like a filthy, pesky fly.

It was as upsetting as it was immediately clear the aide either did not know or did not care about Daddy's debilitation, incontinence or inability to stand. She seemed not to care that he was naked or that the door to his room was wide open. I found this deeply disturbing.

A Pervasive Problem Goes Ignored

In the nursing home where my father was, disgruntled workers herded groups of old people in wheel chairs into open shower stalls and then left them sitting wet and cold in thin coverings for blocks of time that must have seemed like hours. Doctors talked around them rather than to them. Nurses' aides left doors wide open to private rooms while performing very personal procedures.

Beverly Ryan is a registered nurse in San Antonio, Texas, whose 91-year-old grandmother suffered abuse in a nursing home when an aide forced food into her mouth, leaving scratches and bruises. Ryan is a proponent of exposing elder abuse in the media. "If I showed you pictures [of bedsores]—of flesh rotting off bone—you'd think you were looking at something horrible like a Halloween movie, but it's no movie—it's abusive neglect. If we saw these pictures in magazines our perspective would change."

Mike Brogden, retired professor of Criminal Justice and director of the Institute of Criminology and Criminal Justice at Queens University Belfast, and deemed an International Policing Expert, has written the most potent book to date on elder abuse called *Geronticide: Killing the Elderly*. He refers to the seemingly socially acceptable mistreatment of the elderly as "geronticide."⁵

Brogden describes ageism as a market-driven phenomenon manifest in the "privatization of old age." He says the degree of victimization of the elderly comes down to who owns and controls institutional care. In other words, private, for-profit institutions are incubators, he says, for brutal interaction between the elderly and institution employees. In fact, he suggests nursing homes may use planned tactics to render residents powerless. Overmedication is one my father suffered.

One day, Daddy told me the nursing supervisor in charge of the afternoon shift at the rehab center had threatened him when he refused to take drugs he felt he did not need. Like clockwork, she would bring him a cup of pills, but when he refused them finally with clenched jaw, he told how she held the cup to his lips, leaned in within an inch of his eyes and said: "Open your mouth and take it, or else."

Because of his vulnerable physical condition, Daddy was scared to talk about it. When I brought the incident to my family's attention, they insisted I not "cause problems," afraid the facility would discharge my dad and then where could he go? We were a nervous and ill-equipped lot.

About this same time, my mother arranged for her cardiologist to assess my father's condition at his office. Upon ambulance transport and examination, he immediately checked Daddy into a hospital for an overdose. When it came time for Daddy to return to the rehab center, the facility rewarded our discovery of the overmedication with an unexplained, nonnegotiable discharge.

Just as we uncovered the overuse of drugs with my dad in 2005, Percy found decades ago that 35 percent of drugs bought by nursing homes were designed to tranquilize, and more recently, Brogden found that most nursing home residents are given drugs in amounts that rose by 50 percent in 10 years.

Despite urgings to my family to bring Daddy home to recover, my mother—confused, scared, suffering her own medical ailments and relying on a physician's advice—agreed to deposit my father into the dilapidated nursing home from where he regularly phoned and from where I finally rescued him home. It was the first day of June in 2005.

In the beginning, we had to hire home healthcare aides around the clock at a hefty price. But once home, Daddy quickly improved. Still, even at home, with my mom and us just down the hall, instances of abuse continued.

Daddy complained about one aide especially who coincidentally had won my mother's favor. He insisted she was forceful and disrespectful when he was alone with her. I am ashamed to admit his reports fell on deaf ears unable to absorb more stress. We all dismissed his complaints as the grumblings of a rightfully bitter man who had been through a rough ordeal. Only later, after my father died, would we all reflect and concede that what he had tried to tell us was true.

Traditionally thought of as unbiased healing places, hospitals and emergency rooms are not exempt from ageism. From June to September, my father spent several brief stays in the hospital for recurring bouts of bronchitis and other unexpected maladies. During one of the last times, the doctor-on-duty misdiagnosed him with Parkinson's and prescribed hefty medicine with toxic side effects that wound up levying an irreversible toll on Daddy's body, not yet recovered from chemo, and producing among other things sudden fainting.

In October 2005, my father made his final trip to the emergency room after a fainting spell. He would neither leave the hospital nor see home again.

As it happened, the young physician tending to my father in the ER showed us X-rays of Daddy's chest and lungs. The X-rays indicated severe pneumonia, which came as a complete surprise and which the hospital had neglected to detect two days earlier when it dismissed Daddy from a previous admission. Now, the prognosis was certain death.

I asked the doctor, why? If Daddy's condition was ominous, why was he still lying on a cold table in the ER instead of in monitored comfort in the hospital's Intensive Care Unit? The doctor stood silent.

Despite my parents' top-of-the-line insurance coverage with a prominent provider—Daddy was a military veteran and retired civil servant—there he lay, in ER, just waiting to die and us watching him. This seemed all wrong. At even the most basic level of human kindness, do we not comfort the dying? A human being is not road kill waiting to be swept up and the mess disinfected. This was my father.

I pressed the doctor with another question. I asked if hospital policy held an age limit for ICU admission.

The doctor never responded to either question. My family was outraged I would badger the doctor about hospital policy. The doctor disappeared. But soon, an ICU nurse attended to my father in the ER and a short time later Daddy rested comfortably in ICU.

That night, my father died, but not before family and friends gathered to him to bid farewell. He left this world and his contributions to it in dignity, surrounded not by blank-faced strangers but by warm, familiar faces, and the gentle good-byes of whispered kisses and softly held hands.

Sadly, it took constant battling with a sick healthcare system and social mindset to make it so.

The Ugly Truth

In his youth and into his 80s, my father was a hardy man with an equally hardy appetite for life. He was a decorated World War II veteran; a devoted husband and father; an active, lifetime member of his church and neighborhood; a compassionate caregiver to older relatives; and a beloved grandpa, great-grandpa, brother and uncle. He was married and wholly devoted to one woman—my mother—for 60 years and doted on his growing family. Holidays hinged on his barbecues and stories.



But my father fell prey to mistreatment by a “care-giving” culture sick with ageism, even albeit ignorantly administered by our own family. If you think it won’t happen to you, odds are you are sadly mistaken. Statistics say otherwise.

Reminiscent of the Borden case, instead of safe havens, private homes can be breeding grounds for elder abuse, often carried out by overworked, overstressed, unsupported spouses or adult children. Rachel Filinson, author of *Elder Abuse: Practice and Policy*, estimates up to 10 percent of elders living at home suffer abuse by family members or other relatives.⁶

None of us wants to believe it or deal with it. We certainly do not admit to doing it ourselves. Elder neglect and abuse is ugly at its core and appalling. Witnessing it as I have evokes indescribable feelings like the ones we get when watching the news on TV and see paramedics’ gurneys laden with

lifeless bodies after a shooting or when watching commercials showing starving children with bulging eyes and bellies. We see it. We feel bad. But we tend to go about our business as if it never happened.

The unpopular fact is elder abuse and neglect is real and the ageing explosion is making it worse. For the first time in human history, the oldest among us will soon outnumber the youngest. Making matters worse are gross under-estimation by under-funded research resources, under-reporting by abuse victims and apathy by the rest of us.

Secondary to careless medical, rehabilitation and nursing care systems, and admittedly due in large part to ignorance, fear, denial or stress, my family and I also played roles in my father's misfortune. We did not rescue him early on to recover at home. We did not question and confront apparent neglect or abuse every time we saw or heard of it.

While it's true I advocated on behalf of my dad's wishes and brought him home from the nursing home after connecting my mother to home healthcare agencies, I still found myself intolerant of my dad's growing cynicism. In retrospect, I understand it but feel ashamed about the times I lacked compassion.

In short, my family and I found ourselves blindsided at every twist and turn, which were many and constant. Through the morass, we found it very hard to accept two things: First, our patriarch was dying. Second, a healthcare system we grew up trusting was failing him and us and none of us knew what to do about it. What we experienced was neither taught in school nor published with any regularity in newspapers or magazines and certainly was absent in social conversation.

We're All Accountable

Elder neglect and abuse is cunning and pervasive, so much so you may not know it is happening to your parent, grandparent, spouse or other loved one, or you don't realize you are doing it yourself. But it is happening just the same, behind the scenes or openly, in people's homes, in hospitals or in doctors' offices. It is taking place in acute-care facilities, nursing homes, rehabilitation centers and anywhere old people—particularly those who are mentally or physically vulnerable—are left unattended or otherwise shut off from the community and shut in with cruel or indifferent “caregivers.”

In *The National Elder Abuse Incidence Study*, elder-abuse researcher Toshio Tatara defines abuse as physical violence such as hitting, shoving or slapping; sexual abuse involving non-consensual contact ranging from unwanted touching to rape; and emotional or psychological abuse—such as what my father repeatedly suffered—characterized by anguish, emotional pain or distress that stems, for example, from treating older people like infants, isolating them from family or friends, or giving them the “silent treatment.” Abuse also includes abandonment and financial or material exploitation.

As I reflect on what my father endured often with empty eyes and in silence as he watched his body erode, the family he loved and lived for fall apart, and caregivers abuse him, I wrestle with the unsettling memories and struggle to find meaning in his suffering. I only know to tell his story.

But his is not a story about cancer or the debilitation its treatment causes an older person. It is about the shocking consequences for the infirm and vulnerable old in unfamiliar and age-unfriendly places. It is about the reality and subtlety of the many forms and faces of elder abuse and neglect and its precursor: discrimination against the old—ageism. And it is about society’s intense denial it is happening.

When the unspeakable occurred in my father’s deteriorating world, at least he had a telephone and was able to use it to call family for help. He had adult children and a spouse who could respond. But what of countless others like him or in worse condition who have no phone and no one to call?

Given my father’s firsthand experience with elder abuse and abusive neglect, I beg these questions of you who read this story: Where are we as elder abuse and neglect happens all around us? If we do see it happening, are we acting upon what we see and hear or are we unsympathetic and unresponsive? If we are unwilling to confront it, does our apathy make us accessories to the abuse? Finally, are we doing it ourselves?

None of us can escape it—we either die young or grow old. Let us do our part, individually and collectively, to ensure that our parents, others we love, and we ourselves live in dignity in advancing age, free from fear, exploitation, and abuse or neglect of any kind.

“B. Lou Guckian writes a fascinating and personal account of an experience that is affecting millions of Americans,” Brogden says. “Elder abuse is a little-reported and little-recognized form of social harm. The one thing certain in life is death. We can go comfortably with dignity, or we can experience a prolonged experience of indignity and maltreatment on the way. This is an important topic of interest to many people, and B. Lou Guckian writes sensitively and with deep knowledge on this important topic.”

Daddy’s story and countless untold others, like his and worse, are warnings that speak for those who cannot or will not for fear of repercussion. This is not the whispered cry of a single individual suffering in the dark alone; it is a loud collective scream from increasing numbers of our vulnerable old. It is time we unclog our ears and listen—and act.

Will we *budge* from our blissful ignorance about the abuse of our elders—or will the able-bodied among us sit this one out and wait for our turn to suffer?

What You Can Do

The best solution to elder abuse is prevention. While some organizations and families do a good job of caring for their elders, many—perhaps most—do not. It is critical to plan ahead and do your homework before placing an elderly loved one in a public or private institution or hiring domestic caregivers. This is often difficult or impossible when adult children live in different cities, or they lack the necessary time, communication skills or desire to be involved. Still, there are growing numbers of resources available to those who do want to protect their beloved elders.

The best resource is the U.S. Administration on Aging's National Center on Elder Abuse. To locate your State Resource Directory on Elder Abuse Prevention to find out about state government agencies, state laws, state-specific data and statistics and other statewide resources, visit www.ncea.org.

If you suspect elder abuse, neglect or exploitation, you should call the national elder abuse hotline at 1 (800) 677-1116. If the danger is immediate, call 911 or the local police.

Above all, when an older person confides in you that he or she is being mistreated in any way, believe it, confront it, and take appropriate and immediate action to stop it.



In loving memory of Eugene P. Guckian, father of Ms. B. Lou Guckian, a freelance writer and elder advocate in San Antonio, Texas. Read her abstract and complete thesis, "Elder Abuse: More is expected unless society [and mass media] intervene," at www.guckianwriter.com.

Sources

"Elder Mistreatment: Abuse, Neglect and Exploitation in an Ageing America." The National Academies Press, U.S. National Research Council, 2002.

Sara Aravanis, Director, National Center on Elder Abuse. E-mail interview, July 11, 2005.

"U.S. Interim Projections." U.S. Census Bureau, 2004.

"Growing Old in the Country of the Young" by Charles H. Percy. New York: McGraw-Hill, 1974.

"Geronticide: Killing the Elderly" by Mike Brogden. Philadelphia PA: Jessica Kingsley Publishers, 2001.

"Elder Abuse: Practice and Policy" by Rachel Filinson and Stanley R. Ingman. New York: Human Sciences Press, 1989.

"The National Elder Abuse Incidence Study" by Toshio Tatara. National Center on Elder Abuse, American Public Human Services Association for the Administration on Ageing. Washington: 1998.

Find out if you or anyone else is abusing your elders

Answer YES or NO. Have you ever done the following to your elderly parent(s) or other older person(s)?

1. Lost your patience, raised your voice in anger, scolded as if to a child, or threatened in any way?
2. Spoke as if he or she was incapable of making decisions because of old age?
3. Denied spiritual or religious needs or put your own beliefs ahead of theirs?
4. Took advantage of your role as Power of Attorney or Guardian by making decisions for your parents or other older loved ones that they were capable of making themselves?
5. Planned your parents' or other elderly loved ones' future without consulting them?
6. Lied or kept secrets from your parent's or other elders "for their own good"?
7. Borrowed your parents' or other older loved ones' automobile or other property they could no longer use due to old age or illness, and then kept what you borrowed long after you promised to return it, perhaps with no intention of returning it at all?
8. Took food, family heirlooms or money without asking?
9. Made threats to place your elderly parents or other loved ones in a nursing home if they did not behave as you would have them behave?
10. Dominated or directed conversations with doctors or others instead of allowing your parents or other older loved ones to speak for themselves?
11. Denied direct observances or disbelieved and disregarded claims that a doctor, nurse, nurses' aid, domestic caregiver, other family member, relative or anyone else involved in your elderly parents or other loved ones' care, either in a medical facility or in their own home, had threatened or otherwise neglected or abused them in any way, verbally, emotionally or physically?

If you answered YES to at least one of these questions, you have been abusive, whether on purpose or out of ignorance, to your elderly parent or other older loved one, or you have observed elder abuse or neglect and failed to confront it in others. Now that you know, the next time you do it or see it, you will know it is wrong. Learn more about what constitutes elder abuse and neglect and how to do your part to stop it.