

**“They don’t want you to shine the light”**  
**Why Lawmakers and Elder Care Advocates Should Read the book**  
***Locked Out: Elder Neglect and the Keys to Change***

*Review by Eilon Caspi*



Candace Esham wrote this book about “Memom” – her 96-year-old grandmother Mary Claudia Jones Barthelmeh who used to work as a geriatric nurse. She spent 17 years caring for people who were at the end of their life. She loved her profession. In Candace’s words: “Her residents frequently did not have family, and she made sure they all felt valued and received the best care.” Her dedication to the people she cared for was only matched by her inspiring personality and character.

The book describes the many indignities Claudia endured while living in a Delaware assisted living residence and the ongoing neglect of her care that eventually resulted in her painful and traumatic death due to a foot wound sepsis and MRSA (Methicillin-resistant Staphylococcus Aureus). Candace writes: “Memom had to have been in incredible pain during the time leading up to her death.” She adds that she had lost her Memom “in this terrible tragedy.”

It describes the inhumane suffering Candace and her mother Lucilla had gone through as they desperately tried to support Memom and ensure she receives professional and dignified care (“It is hard to put into words how heartbroken I am that Memom was treated this way” / “I have nightmares reliving seeing her in that pain” / “I miss Memom every day”). Candace’s deep love for her grandmother is felt throughout the book (e.g., “I held Memom’s hand and told her that so many people loved her throughout the years”).

The book describes the shock Candace experienced when she discovered how long Memom suffered when she was neglected by the assisted living residence (“I couldn’t have been more shocked by how long Memom had been suffering”).

It is a story of trust that has been broken. It is a story of an unfulfilled [promise](#). Candace writes: “I trusted healthcare providers would make the best decision for Memom.”

It describes how the soul crushing isolation – while being confined in a 10-foot by 20-foot bedroom – contributed to Memom’s ongoing suffering and steady decline (e.g., “She looked crushed, spending the day isolated from friends and family” / “With each passing week, we could see the strain of isolation”). While the book primarily focuses on Memom’s experience, it represents “The devastating impact of isolation on elders” in care homes across the country.

It describes the ways in which Memom’s family was left in the dark despite repeated efforts to find out how she was doing, what was her state of well-being and physical function. It also describes how critical information about her physical condition was kept hidden from the family. For example, Candace writes: “The nurses documented her foot wound starting September 2020 but did not let us know of the situation until a couple of months later.” She adds: “Had we understood the severity of her wound, we would have challenged their decision to keep her at the facility.”

The assisted living residence also delayed critical interventions for Memom (e.g., a cardiologist discovered Memom’s foot wound during a routine visit and recommended that she will be seen emergently by a podiatrist. The visit was not documented until a month and a half later).

The book illustrates the ways in which ageist perceptions prevented Memom from receiving essential interventions (e.g., “Your grandmother wouldn’t benefit from mental health help.” A physician in the hospital asked if Memom was “worth saving”).

The book demonstrates how painfully impossible it was for locked out families to see, visit, and advocate for their loved ones in long-term care homes during the COVID-19 pandemic (e.g., “Preventing families from being able to check on their loved ones is dangerous” / “Locking families out created more harm than good.” / “We didn’t even get to see her on Christmas through a window”). It is a story lawmakers must hear so they’ll understand why the Essential Caregiver Act must pass. For details, read this [summary](#) and watch this heartbreaking [video](#).

The family paid \$7,000 each month to ensure Memom would receive professional care. Instead, Memom suffered horrific neglect and her family was left traumatized and devastated.

Like an X-ray, the book reveals the many and longstanding flaws in the for-profit but weakly regulated assisted living sector and the urgent need for a comprehensive life-saving reform.

It shows how the assisted living residence operated outside its scope of practice when it provided services for Memom despite her having a wound at a severity level beyond what they were licensed by the state to provide (“The facility was not allowed to treat a resident with a stage 3 or 4 pressure ulcer without a waiver from the family”). Memom’s wound was “unstageable,” which means “the dead tissue, black in appearance, completely covers the wound.”

The story describes the guilt scores of invisible families suffer when despite all their advocacy efforts, their relatives are severely harmed. Candace writes: “I blamed myself for losing Memom.” She adds: “My family has carried the guilt of not knowing my grandmother was suffering and trusting she would be safe in a facility.”

It describes the family’s ongoing efforts to find out what has led to Memom’s death. “All I could think about were the unknowns that led to her suffering. I wanted answers,” she writes.

It shows how Memom’s extremely painful death could have been prevented at multiple points in time (“I believe Memom’s death could have been prevented” and “There were so many opportunities for someone to step in and get Memom proper treatment”).

The book illustrates how [fear of retaliation](#) prevents families from complaining about poor care and neglect (“I began to wonder how many other families decide not to investigate neglect for fear of retaliation”). This fear is [similar](#) to the one experienced by elders in nursing homes.

It describes the family’s motivation to file a complaint with the State Survey Agency (“The day after Memom’s death, I knew a complaint investigation needed to be completed to prevent others from suffering the same outcome”).

Candace's motivation for writing the book was similar: To "prevent others from suffering neglect" ("I am heartbroken and will continue advocating so others do not have to suffer like she did" / "I felt desperate to give Memom's suffering a purpose").

The book sheds light on the weak state oversight and enforcement of the assisted living sector, which is the case in the vast majority of states ("Systemic issues in the care for seniors are not unique to Delaware"). Candace states: "Lack of oversight in long-term care facilities by government agencies allows neglect and harm to continue."

Examples of the failing oversight in the state of Delaware as described in the book:

Lack of lawmakers' meaningful action to address chronic systemic problems ("It seemed overwhelming how problems could exist for decades, and yet there were no legislative actions taken to address them"). For example, at the time of the writing of the book, the state of Delaware did not have regulatory standards related to Dementia Care services (such as minimum staffing levels and staff training). Candace writes: "Dementia care wasn't currently defined in Delaware code and, therefore, did not require specific license for care."

The state oversight failed to hold assisted living residences accountable. For example, there was a low frequency of state inspections in a subgroup of assisted living residences (It "failed to inspect many facilities for a handful of years"). Specifically, "Only two assisted living facilities were surveyed in 2018 and 2019 each year" and "30 of the 43 [assisted living residences] have not been surveyed in over a year." And "in 2021, only 22 "annual" surveys were conducted out of the 81 total skilled nursing homes and assisted living facilities." Referring to the annual inspections required in nursing homes, Candace writes: "We believe aligning assisted living facility survey frequency is critical to ensuring the safety of residents and quality of care."

The state also had a "decade-long [struggle](#) with investigating complaints." For example, there were delays in state investigations of serious neglect allegations in assisted living residences. Memom's complaint "had still not been investigated more than five months after her passing" (the complaint was filed a day after she passed away). Candace writes: "Without completing it in a timely manner, other residents in Memom's assisted living were vulnerable to harm."

The confirmation of Memom's neglect came only 334 days after Candace submitted the complaint to the state "but the assisted living has failed to put forward an acceptable corrective plan three times." Candace was "outraged at the lack of urgency to investigate the complaints." She asked: "Would you accept this response if your child or dog were treated this way and no actions were taken over a year later?"

Serious questions have also been raised about *the quality* of the state investigation of Memom's death. For example, the state investigated Memom's neglect but the surveyor "found no issues and they were closing the case." Candace wrote: "I was shocked to learn she hadn't requested any medical records. Only interviews with the staff at the assisted living facility were conducted to lead to the conclusion that nothing wrong had happened."

These systemic oversight problems may not come as a surprise as the Delaware State Survey Agency was “underfunded” from 2013 to 2019 and it had an approximately 50% surveyor vacancy rate in August 2022.

Candace concluded: “Lack of oversight and inadequate penalties for violations in long-term care facilities can cause grave danger to our most vulnerable populations.”

The book sheds light on the decades-long lack of transparency regarding the quality of care and safety of vulnerable individuals in the assisted living sector. Candace writes: “Based on our collective experience with the coalition, most families did not have an informed plan for their loved ones for aging due to lack of publicly available data and had to use what they could find to decide where to put their family member.” She adds: “Access to information on the safety and quality of facilities is critical for families to make informed decisions on where to have their loved one live...” She went on to make the following recommendation: “Create transparency and accountability for surveys and complaints in facilities to allow easy public access to make informed decisions on care.”

The book illustrates the gross asymmetry of power that exists between the assisted living industry and families as they advocate for systemic changes and protective legislation. One common example is that family members are often being outnumbered by the long-term care industry representatives and lobbyists during key meetings and hearings. Candace writes: “I could see the outer chairs around the room full of long-term care facility lobbyists...” / “Once again, I felt outnumbered and prepared for the bill content to be picked apart. The meeting lasted almost two hours, with most of the conversation driven by industry representatives” / “Once again, the industry representatives dominated the conversation with reasons why the bill was burdensome and would harm their business” / “How challenging it was to be a voice on a Task Force when she was the only member of the public.”

It is a story of faith and perseverance in general and despite substantial personal and professional sacrifices as many family members are often forced to strike a delicate balance between their full-time day jobs and advocating for their loved ones’ dignity and safety.

It describes the frustrations Candace and her mother experienced when trying to advocate for legislative changes in the assisted living sector. She writes: “Mentally, I couldn’t face any more meetings where I poured out my heart begging for changes only to hear excuses about workforce shortages, funding, and the pandemic.” Specifically, the book describes the assisted living industry’s playbook of messages designed to block real progress with sorely needed legislative changes in this for-profit but weakly regulated care sector.

Candace writes: “The same excuses the industry brought up in these meetings were what caused me to take a break from advocacy.” “Furious with the gaslighting by the industry,” she also identifies a valuable lesson: “Always anticipate the argument from opponents to change and research the facts.”

The book is based on data-driven advocacy driven by the author's translational knowledge and skills being an engineer in the nuclear power industry, healthcare, and chemical manufacturing industry. Candace writes: "I was trained in root cause analysis for my engineering roles." She adds: "The research behind the recommendations proved to be beneficial." In terms of gaining access to critical data through FOIA requests, she writes: "The wait was worth it."

It is a story that highlights the importance of following your instincts and using common sense to challenge statewide policies that are unbalanced or ones that do not make sense. For example, regarding the state COVID-19 vaccination distribution: "This is an insane and inhumane way to treat our most vulnerable population."

It illustrates the importance of learning from policies and best practices used in other states. For example, Candace writes: "Florida's handling of the pandemic was vastly different from Delaware's management." She adds: "Modeling best practices from other states provided the platform for steps toward improving quality care."

It describes the need for legislation that focuses on prevention and the need to shift away from a reactive approach. For example, Candace writes: "This bill actually focuses on a proactive approach to best practices rather than reacting to a tragedy with a plan of correction."

The book demonstrates the critical role of investigative reporting in families' advocacy for changes in state regulatory standards of assisted living residences. During her advocacy, Candace believed that "press coverage of the systemic issues in the long-term care industry would drive change and prevent others from suffering neglect." She writes: "I was convinced a front-page story would be the only way to drive legislative changes." She was right: "The media coverage of the package established improvements to quality care for seniors as a priority for this legislative session." One investigative journalist [Meredith Newman](#) dedicated 18 months to writing a series of articles exposing the neglect and lack of oversight. It "drew legislators' attention to the long-standing issues with survey frequency, complaint backlog, and harm."

It is an inspiring story of transformation from grief to effective state-level advocacy for change. Candace writes: "I promised to advocate for systemic changes in long-term care facilities." Referring to her grandmother, she writes: "I know she would want me to pursue advocating for others in her honor." She adds: "Once I decided to develop a strategy with my coalition and develop solutions, there was a shift in how I carried my grief."

Memom's horrific experiences have led Candace to found [Delaware Elder Care Advocacy Coalition](#). Joining forces with family members of other individuals who were harmed in Delaware long-term care homes ("There is power in numbers") enabled the group to make significant steps towards balancing the asymmetry of power and pass several bills that could improve the care and safety of thousands of elders in long-term care facilities. In Candace's words: "A commonality between all of us was the devastation from harm to our loved ones and frustration with oversight and accountability for quality care." The Coalition "was formed by families who share passion for driving legislation for aging residents to ensure quality care."

She describes one of her key strategies: “Build a network of allies who share the vision for a better care system and can amplify the voices of the team of advocates.”

Candace’s story resembles the journeys of families in other states who for years have been fighting to strengthen regulatory standards in the assisted living sector. One strikingly similar example is Kristine Sundberg, Executive Director, [Elder Voice Advocates](#), Minnesota.

Candace’s story must be known to every member of the U.S. Senate Special Committee on Aging, which held a [hearing](#) in 2024 about the systemic issues in the assisted living sector.

Strikingly similar systemic issues were known to the same Committee over two decades ago as described in the 2003 Assisted Living Working Group [report](#) and has been tragically demonstrated in many [deadly neglect](#) incidents that have taken place in this care sector since.

Candace’s meticulous documentation of key steps in her advocacy journey created a precious roadmap for change. Lawmakers, elder care advocates, family members, and individuals receiving long-term care in other states could learn from Candace painful experiences and lessons learned to strengthen their advocacy efforts and make them more efficient and impactful. This, beyond the red flags and signs of neglect other families should pay close attention to when supporting their loved ones who are living in assisted living residences (these are described in detail throughout the book).

Since the story will likely resonate with hundreds of thousands of families across America, the book strikes me as having the material for a documentary film.

“Aging with dignity is a basic human right and how we should all aspire to be treated,” Candace writes in her book.

The book is available on Amazon:

<https://www.amazon.com/Locked-Out-Elder-Neglect-Change/dp/1966625014>