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On Film and Digital Media

Life and Death in Assisted Living

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Film: *Life and Death in Assisted Living* (53 min)

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Producer: Carl Byker

Written by: Carl Byker and A. C. Thompson

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Distributor: PBS

The film *Life and Death in Assisted Living* (PBS Frontline and ProPublica, 2013: https://www.pbs.org/wgbh/frontline/film/life-and-death-in-assisted-living/) examined the care practices of Emeritus Corporation, which at the time was the country's largest assisted living (AL) company. In 2012, the for-profit chain had nearly $1.6 billion in revenue.

The PBS/ProPublica investigation of Emeritus revealed systemic neglect resulting in the death of several older adults with dementia. The film describes the traumas experienced by the residents caused by these incidents and the devastation to their families. The thorough investigation examined extensive evidence, including clinical and court records, state investigation reports, and interviews with family members, former employees, and experts. The film will likely be an eye-opener to viewers unfamiliar with the AL model and its flaws. The film itself is of high quality. It is visually and substantively captivating. The horrific stories of neglect described in it will give viewers a strong emotional reaction.

Here are some of the incidents covered in the film:

- George McAfee lived with dementia in AL in Georgia. One night, he drank from an unlocked bottle of industrial strength dishwashing liquid. He died after the chemical burned his lips, esophagus, and lungs. The state found Emeritus negligent in his death and fined the AL company $601. His daughter reported, "He suffered a horrific death." She added that the fine was "outrageous" and that, "Had this been a day care facility or a child died, the place would have been shut down."
- In Colorado, Herbert Packard's family paid $5,000 a month for his care. One day he was beaten by a resident with brain damage after walking into his bedroom. He suffered a broken hip and brain bleeding and died 2 months later. The state cited the AL for failing to protect him and fined Emeritus $500.
- Mabel E. Austin lived with dementia in AL in Texas. On Christmas night, she left the AL residence and froze to death.
- In Florida, Richard Borrack, who had Alzheimer's disease, left the AL residence never to be found.
- In Mississippi, Merle Fall, who had dementia, forced herself through an upstairs window and fell to the ground. She sustained brain bleeding and died 3 days later.
- In California, Joan Boice lived with dementia and required extensive assistance in walking and eating. She was admitted to an AL residence against employees' opinion that she needed skilled nursing home care. Her condition declined and she moved to a nursing home where doctors discovered "life-threatening" pressure ulcers. The family filed a lawsuit against Emeritus. All 12 jurors found the corporation liable for "recklessness, oppression, and fraud" in Boice's wrongful death. Emeritus was required to pay punitive damages of nearly $30,000,000.

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Interviews with former Emeritus employees and a review of records revealed failures in key areas. Examples highlighted in the film included the following:

- Dangerous staffing levels (a top executive testified, "They were constantly being told to cut labor expenses").
- Grossly insufficient dementia care training (Emeritus staff orientation training consisted of only 8 h in its "memory care" homes).
- Tremendous pressure to fill up beds (a lead salesperson said, "The biggest thing I always heard was '100%, we need 100% … always fill the building … 100%'").
- Admitting residents with complex health conditions the AL residence could not care for: "They are bringing nursing home patients to an assisted living facility," said a director of a memory care unit.
- Coverups (a boss telling an employee unqualified for treating a resident's serious pressure sores: "Just don't let anybody know").
- Deep concerns by employees regarding residents' care and safety. One nurse described her AL residence as "very dysfunctional" and "a sinking ship" while another employee described her AL residence as "a boiler about to explode."
- Retaliating against employees and managers who sounded the alarm fearing harm to residents (three employees reported being fired).
- Deceptive marketing practices.

In the film, Catherine Hawes, a national expert in quality of care in long-term care (LTC) homes, shared her views on the AL industry:

> We're creating an industry with a million people in it who are becoming more frail, who are poorly regulated by the state … that's why I talk about it as a ticking time bomb because we're going to see more deaths, more injuries, and families are going to be so shocked because they think they've made a good decision, they think they've made a safe decision.

Background and Evolution of AL

AL has been and continues to be the fastest growing residential care option for older adults in America (Ball et al., 2004; Thomas et al., 2020), and dementia care is the fastest growing segment of this sector (Rau, 2018). It is the home of approximately one million people. An estimated 30%–42% of AL residents have a diagnosis of dementia (Sengupta & Caffrey, 2020; Thomas et al., 2020). In addition, an alarming portion of AL residents require assistance with activities of daily living (ADLs) such as with bathing, walking, dressing, transferring, and toileting (nearly two-thirds of residents needed assistance with three or more ADLs) while many have complex health conditions (Caffrey et al., 2021). In short, in recent years, the AL population increasingly resembles the nursing home population in physical frailty and cognitive disabilities (Kaldy, 2018; Laxton, 2019).

Certainly, some AL residences provide dignified, professional, and safe care. However, systemic problems and mistreatment in the AL industry have been repeatedly reported over the years (Caspi, 2018b). In fact, experts believe that "an unconscionable number" of AL residents with dementia experience "neglect, abuse, or harm" (Kaskie et al., 2015), which is consistent with extensive evidence showing a greater risk of mistreatment of this population in LTC homes (Mileski et al., 2019).

While the actual scope of mistreatment such as neglect in AL is unknown, a small body of research suggests that it is "significant enough to be of concern" (Phillips & Guo, 2011). For example, a large-scale study found that safety culture in AL is low and the potential for neglect of residents with dementia is high (Castle et al., 2012). In addition, findings from a nationwide survey suggest that tens of thousands of AL residents may experience harm or physical abuse each year (Castle, 2013). Furthermore, a study by Page et al. (2009) found that rates of neglect of AL residents with dementia were very high (19%).

The available evidence suggests that mistreatment in AL is not because of "a few bad apples." When considering these findings, it is important to recognize that the majority of older people's mistreatment cases in the community and LTC homes are not reported (Mileski et al., 2019) and are seriously underidentified in AL (Phillips et al., 2013). Residents' cognitive disability and fear of retaliation (Phillips et al., 2013), which is not uncommon in AL (Robison et al., 2007), poor nursing assessment and documentation practices, lack of screening for neglect, among other factors (Wood & Stephens, 2003), account for this situation.

Several media reports have also called attention to serious neglect in AL (Callea, 2003; Rau, 2018; Serres, 2017a; Span, 2019; Teegardin & Schrade, 2019). Beyond the alarming scope and severity of mistreatment identified in an investigation entitled *Left to Suffer* in Minnesota (Serres, 2017a), investigations in Georgia (Teegardin & Schrade, 2019) and in San Diego County (Clark & Sisson, 2013) found dozens of injurious and deadly neglect incidents in AL homes. These three investigations also found poor state oversight and enforcement of AL settings.

The failure of a subgroup of AL to provide safe care is often exacerbated by limited state regulations, weak oversight, inadequate investigation capabilities, and minimal enforcement (Hawes & Kimbell, 2009; Office of the Legislative Auditor of Minnesota, 2018). With regard to enforcement, insignificant penalties and sanctions for serious violations in the care of AL residents in general and those living with dementia have been previously found to be common (Kaskie & Kingsley, 2009; Teegardin & Schrade, 2019). In addition, limited Ombudsmen presence in AL reduces residents' ability to know and realize their rights and be protected from mistreatment (Hall et al., 2021). In 2019, nearly 70% of nursing homes were visited at

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least quarterly by Ombudsmen compared to only 30% of AL residences (National Ombudsman Reporting System, 2019).

Another factor contributing to these failures is the extreme lack of transparency of most AL companies. Transparency is the foundation for consumers' informed choice (Teegardin & Schrade, 2019) and AL accountability (Government Accountability Office, 2018).

The review of state AL regulations by Kaskie et al. (2015) concluded, "assisted living appears to be failing when it comes to protecting residents with dementia." The review also found that "states have fallen short in successfully assuring that assisted living residents with dementia are protected from neglect." The authors identified gaps in many states' AL regulations such as in the areas of safety, staffing requirements, and dementia care training.

While significant increases in many states' AL regulations have been realized between 2003 and 2018, major gaps in requirements, oversight, and enforcement remain (Carder et al., 2019). In addition, an examination of regulations in 50 states has shown that substantial variation in scope and quality of AL regulations pertaining to key aspects of dementia care continues to exist across states (Carder, 2017). The study found that most states "rely on general residential care/AL regulations to cover dementia care policies and practices" and most states do not address many basic issues essential to caring for residents with dementia. The researchers stated that such regulatory inaction may contribute to arbitrariness, increased public and private costs, differing and conflicting expectations about services and state oversight, lack of adequate protection against substandard care and mistreatment, and limited AL accountability.

It is therefore not surprising that states' failure to oversee AL has continued in recent years (Office of the Legislative Auditor of Minnesota, 2018; Serres, 2017b; Teegardin & Schrade, 2019). In some cases, systemic failures in care and oversight culminated in new protections and stronger oversight (Serres, 2021). However, to my knowledge, since *Life and Death in Assisted Living* aired in 2013, not much has improved in the AL industry with regard to the quality of care, neglect, abuse, financial exploitation, theft of opioid pain medications, and safety.

While basic data on AL residences in many states are lacking, this look-back reflection on the 2013 PBS/ProPublica film is based largely on my examination of hundreds of investigation reports that were substantiated by the Minnesota Department of Health as neglect in recent years (2014–2019). My examination revealed neglect in dozens of AL residences resulting in serious physical injuries, emergency room (ER) visits, hospitalizations, and deaths (Caspi, 2021a; Elder Voice Family Advocates, 2019). Similar outcomes in AL residences (e.g., lack of staff knowledge in preventing and assessing acute illnesses, limitations in monitoring changes in residents' conditions, injury, ER visits, and hospitalizations) were found in previous research (Phillips & Ziminski, 2012; Sharpp et al., 2012).

My examination also identified theft of money, jewelry, and opioid pain medications belonging to nearly 250 AL residents (Caspi, 2021b; Span, 2021). Increased attention to thefts in AL is warranted due to the lack of research on these crimes in this care setting and a study showing that complaints related to financial exploitation were higher in AL than in nursing homes (Magruder et al., 2019).

Recently, Kristine Sundberg, executive director, Elder Voice Family Advocates, watched *Life and Death in Assisted Living* and shared her reaction to it (K. Sundberg, personal communication, May 10, 2021):

> This was filmed in 2013 but could have easily been filmed in 2021. My fear is that it can be replayed without editing in 2031. Understaffing was key then as it is now, but much more serious with the pandemic. Catherine Hawes calls assisted living the "ticking bomb" but it is really an expansive mine field for the residents and their families.

Many of the recent incidents of neglect in AL residences in Minnesota are strikingly similar to those that took place at several Emeritus AL residences a decade ago. What follows is a description of just a few incidents.

- A resident with severe cognitive impairment requiring complete assistance with ADLs fell during an unsafe staff transfer. The resident crawled on the floor without underwear while soiled with feces. Camera footage showed staff watching TV, reading a magazine, and leaving the area several times. There was no attempt to assist the resident for 3 h and 49 min.
- A resident requiring assistance with toileting went to the bathroom at 02:00 a.m. The over-the-toilet commode was too small causing the resident to become wedged on the toilet. She pressed on the call pendant and screamed for help. A staff member was asleep. The fire department arrived at 05:00 a.m. to assist her off the toilet.
- A 90-year-old woman with Alzheimer's disease called for assistance for over 39 min. She then fell off her bed and called for help 143 times. At some point, she cried out, "Please help me Lord." Her daughter saw it on a hidden camera and alerted staff. Later on, she reflected, "Something is fundamentally wrong with a system that allows an elderly woman, anyone elderly, to be disregarded" (Lyden & Michael, 2021). The family paid $6,810 each month for her care.
- A resident with dementia whose wellness checks were not done left the AL residence and was found dead in a pond.
- Unsafe manual and mechanical lift transfers resulted in several injurious and deadly falls.
- Two residents died due to pressure sores left untreated.
- The catheter of another resident stopped draining. The resident contracted *Escherichia coli*, developed septic shock, and died.
- Two residents with diabetes died after high blood sugar levels (540 and 765 mg/dL) were left untreated.

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- Delays in recognition of strangulated hernia led to the death of a resident.
- Medication errors resulted in the death of several residents.

Lack of supervision resulted in the death of multiple other residents:

- Two residents with dementia fell down the stairs and died of their injuries.
- Care employees were unaware that a resident with dementia moved into the "memory care" home 18 h earlier. The resident was found dead with her head wedged between the toilet and wall.
- Three residents with dementia in different AL residences gained access to cleaning supplies left unattended or unlocked. They ingested them, suffered severe burns, and died.
- A resident with dementia died a month after sustaining a hip fracture when she was pushed by another resident with dementia who had a long history of "physically abusive behaviors." The AL residence failed to provide supervision, risk assessment, and interventions in the weeks prior to the incident. Despite being prevalent, only limited research has examined the phenomenon of resident-to-resident incidents in AL (Castle, 2013; Caspi, 2015, 2018a, 2021c; Gimm et al., 2018; Scheidt et al., 2020).

Conclusion

As predicted by Hawes (Breslow, 2013) and McGinnis (2014) nearly a decade ago, in recent years, we have seen serious neglect in a significant number of AL residences. A dangerous combination of factors—residents' physical and cognitive disability, complex health conditions, poor staffing levels, high staff turnover, grossly insufficient dementia care training, inadequate administrators' qualifications and training, admitting residents without the ability to care for them, limited nurse and physician involvement (e.g., basic and risk assessment, supervision, and guidance to direct care staff), poor care coordination, lack of adequate monitoring of and timely response to a significant change in condition, inadequate communication with family members, lack of transparency, deceptive marketing practices (Kane & West, 2005) and weak state regulations, oversight, and enforcement—accounts for this continued neglect.

Taken together, states and Congress must take a hard look at the AL industry and implement meaningful policies and legislation to protect vulnerable and frail residents from harm. Otherwise, Sundberg's fear that the film, *Life and Death in Assisted Living*, could be replayed without editing in 2031 could become a reality. Years ago, a director of a state licensing agency reported, "Assisted living is the rock we don't want to look under" (Breslow, 2013). It is time to turn over the rock.

Several years ago, Kaskie et al. (2015) urged our federal leaders to assign the Centers for Medicare & Medicaid Services responsibility for AL by (a) "creating a set of national standards" concerning the conditions, staffing levels, care processes, and resident outcomes and (b) designing a surveillance system (e.g., annual inspections and complaint investigations) to ensure that every AL residence "meets a minimum set of national standards." These authors believe that an increased federal interest "could improve existing state efforts to protect persons with dementia in AL."

Other experts have also called for increased public scrutiny, quality assurance processes, and standards of quality of care in AL (Hawes & Phillips, 2007), regulations that account for the unique needs of AL residents with dementia (Carder, 2017) while researchers studying mistreatment in AL asserted, "objective and public oversight" of AL "is badly needed" (Page et al., 2009).

Similar concerns and calls to action were made by care advocacy groups (Association of Health Facility Survey Agencies et al., 2003), other stakeholders (Assisted Living Work Group, 2003), and lawmakers (U.S. Senate Special Committee on Aging, 2003) nearly 20 years ago.

The tragic incidents in recent years make it clear that vulnerable and frail AL residents with dementia and/or complex health conditions can no longer wait for their states to realize their duty to protect them. Neither can they wait for low-performing AL companies who are "taking an ostrich-like posture" when they refuse to acknowledge systemic quality of care problems (Pace & Love, 2008) and refuse to see themselves as providers of health care and medical services (not only social services; Carder et al., 2019; Kaldy, 2018; Kane & West, 2005; Laxton, 2019; McGinnis, 2014). It is important to reiterate, "as residents entering assisted living communities are becoming increasingly frail and medically complex, the challenge of providing patient-centered care within an interprofessional framework has increased proportionally" (Kaldy, 2018).

In accordance, in recent years, care professionals, researchers, and experts have been calling for stronger integration of the nursing profession (Caspi, 2019; Wallace, 2003) and the medical profession into AL residences (Dys et al., 2020; Laxton, 2019). For example, Sheryl Zimmerman, an expert on AL, asserted, "There has to be more attention to medical and mental health care in assisted living." She added, "There can be health care in assisted living without making it feel like a nursing home" (Span, 2019).

Furthermore, consumers' concerns about the overreliance of AL residences on their internal quality assurance processes, satisfaction surveys, and market forces as primary means to assure quality and safety have been longstanding (Hawes & Phillips, 2007). Moreover, recognizing that "accountability has been lacking in assisted living," Douglas Pace, director, Mission Partnerships, Alzheimer's Association, and Karen Love, cofounder of

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Center for Excellence in Assisted Living and executive director, Dementia Action Alliance, asserted, "waiting until a crisis strikes to make needed changes is shortsighted and disingenuous" (Pace & Love, 2008).

Despite these continued concerns, beyond some significant changes in certain states' AL regulations in recent years (Carder et al., 2019), serious gaps in key areas related to dementia care remain in most states (Carder, 2017), and there has still not been a major reform in the AL industry.

Throughout the years, we frequently heard about the core principles of the AL model—"independence," "autonomy," "dignity," "choice," "home-like, "nonmedical," and "aging in place"—as reasons why basic professional nursing care standards and meaningful legislative protections against mistreatment should not be adopted by states and Congress for AL. The deadly neglect incidents described in this review clearly violate these core principles as well as the bedrock principle of safety we all expect in our own homes. The rivers of tears and broken hearts of family members who have lost their loved ones due to neglect in AL residences indicate that the promise of this care sector as a safe LTC alternative to nursing homes continues to be unfulfilled in a subgroup of AL providers (Caspi, 2021d).

Over a decade ago, a resident living with early-stage Alzheimer's disease asked during my study in a secured dementia care home operated within an AL (Caspi, 2014, 2015), "Why can't we make our voice go through the walls of this building?"

Will our state and federal leaders *finally* listen to the voice of vulnerable older adults with dementia and their families, recognize the chronic and systemic problems in the AL industry, commit to a bi-partisan collaboration, and act to ensure that adequate protection against mistreatment will be implemented? The public's trust in the AL industry and the safety of a million people living in this LTC sector are at stake.

In closing, Jean Greenwood, a survivor of neglect of her mother, spoke during a memorial service she led (Elder Voice Family Advocates, 2021) on the same day (August 1, 2021) the first AL licensure in Minnesota went into effect (Leamanczyk & Eckert, 2021; Minnesota Statutes, 2021). She said:

> Many of us are here today because we discovered a truth that not everyone knows—that the quality of care for our elders has often been grievously substandard. Many of us learned this truth the hard way, through personal experience, which led us to fight for assisted living licensure, because we don't want anyone else to suffer the way our loved ones suffered, as well as we and our families.

The hope is that the new protections against mistreatment and stronger oversight of AL in Minnesota will result in safer AL care environments for vulnerable older adults.

Consider Using the Film to Raise Awareness, Educate, and Advocate for Change

As this review demonstrates, the film *Life and Death in Assisted Living* is still as relevant today as it was when it aired in 2013. Owners, administrators, care professionals, and educators in AL residences can use the film to raise care employees' awareness to the systemic problems in a subgroup of low-performing AL residences and hold open discussions about the measures taken by the AL residence to address them. In addition, care advocates can use the film to raise public awareness to these issues so that consumers—prospective and current residents and families—will become more vigilant when looking for a safe AL residence and advocate for a safer care environment during their residency. Policymakers and lawmakers can use the film when advocating for stronger state and federal protections, oversight, and enforcement in the largely for-profit AL sector.

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