Home [bound]

A Thesis Project

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by

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I would like to thank…

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PREFACE

In the context of this work, it is important to note the distinction of language used to describe aging, and older individuals throughout the text. Lacking a clear definition of aging within the United States, there is dispute over what label(s) should be constituted as appropriate to denote someone of an old(er) age.[1] There does seem to be a relatively universal distinction between *older,* and *old* individuals however, with the first typically meaning a range between age fifty and seventy-five, and the latter meaning age seventy-five to death.[2] The actual numerical age of an individual is not what makes this distinction, but rather the onset of what we perceive to be *fragility*, eventually leading to *dependency*. Many fifty-year olds, and even seventy-five year olds are still climbing ladders to clean the gutters and exceling in their Pilates classes. Typically, when someone is deemed as fragile is when they become *old*, and when they must rely on others and can no longer fully care for themselves, they become *elderly* or *senile*. Of course as life expectancy changes, so will these ranges, and they can never be all inclusive, as aging is a process exclusive to each person. Peter Laslett, an English historian who devoted a great deal of time to the study of aging, coined this concept as the division between the *Third*

[1] Lawrence Samuel, *Aging in America: A cultural history* (University of Pennsylvania Press, 2017), 2.

[2] These numerical values are somewhat arbitrary however. Each individual ages at their own pace depending on a host of different factors, and even governing entities have struggled to define an exact age for 'senior citizens'. Americans qualify to be an AARP member at age fifty, but some businesses do not validate senior discounts until the age of fifty-five or even sixty-five. Medicare enrollment begins no earlier than age sixty-five, but one can choose to start drawing from social security anytime as early as age sixty-two, but caps off the increasing monthly benefits at age seventy.

Hartman, Rachel. "When Do You Become a Senior Citizen?" U.S.News & World Report. August 10, 2022, https://money.usnews.com/money/retirement/aging/articles/when-do-you-become-a-senior-citizen.

Age and the *Fourth Age* of life, contrasting between times of 'activity and fulfillment', versus the prior discussed 'dependency and frailty'.[3] For the purpose of this text, any labeling of an old or older individual primarily refers to the experience or anticipation of the Fourth Age. *Older* or *aging* American(s), individual(s), or person(s) seems to be the most appropriate use of language, but occasionally *senior(s)*, *elder care*, and *geriatric (care)* may be used as well.

Additionally, in the sake of this paper, the terms *nursing home, long-term care facility, skilled nursing facility, skilled care facility, specialized care facility, geriatric care facility, elder care facility, elder care home,* or other variations shall all be synonymous unless stated otherwise. Any of these terms further specified as *memory care*, denotes a facility or nursing home that specializes in the treatment and care of individuals with dementia. Similarly, the term *dementia* shall be considered interchangeable with *Alzheimer's disease* or *Alzheimer's type dementia*.

INTRODUCTION [conception]

Over three quarters of older Americans wish to die at home,[4] largely due to the stigma surrounding life within nursing homes—yet only one third actually do.[5] Inadvertently omitting a sense of comfort and normalcy for their residents, especially for those with Alzheimer's type

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[3] For more information on this, read Laslett's 1989 book, *A Fresh Map of Life*, which goes into heavy detail about the defining of age through an individual's respective mental and physical health in each stage of life.

Samuel, *Aging in America: A cultural history*, 6.

[4] Joanne Binette and Kerri Vasold, "Home and community preferences: A national survey of adults age 18-plus," *AARP Research* 40 (2018).

[5] Henry R. Olaisen, "QuickStats: Percentage of Deaths,* by Place of Death†—National Vital Statistics System, United States, 2000–2018," (2020).

dementia, many nursing ‘homes’ carry a negative connotation. Despite this strongly ingrained resistance, a second third of Americans now end up passing in one.[6] The question is, *why?*

THE HISTORY [birth]

The negative culture of aging that exists in America today spans back to the turn of the twentieth century. In *Aging in World History*, the first written comprehensive global history of aging, author and historian David Troyansky argues this era as when old age was first regarded as a ‘social problem’ rather than an esteemed title.[7] Revolving primarily around domestic structures available to working class families and production culture, the societal norms of household and workplace organization have created a standard of isolated aging that older Americans now face.

Throughout the seventeenth to early nineteenth centuries in the United States, old age was a status symbol—something to be revered. This is mostly because life for the common class was hard,[8] so to reach the age of even seventy was rare, making it highly admirable.[9] The gradual shift towards perceiving aging as a negative process rather than an endearing one can be attributed to a general increase in life expectancy, but also is largely contingent on socio-cultural changes that have taken place over the last two hundred years.

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[6] Olaisen,

[7] Samuel, *Aging in America: A cultural history*, 7.

[8] Often even for royals and the wealthy elite, when compared to today’s standards of medical technology and general hygiene and well-being practices

[9] Samuel, *Aging in America: A cultural history*, 7.

Nineteenth century ideals positioned young, ambitious men as the promising makers of the nation, leaving women[10] at home to tend to domestic duties, including caring for aging parents who could no longer function in their prescribed roles within society. Growing old during this time still typically meant *aging-in-place* however, the concept of living in one's home until death, only temporarily residing elsewhere for serious health issues requiring hospitalization. In this time period, even funerals were held in the deceased's home.[11] Many historic New England residences had a *coffin door*, an opening leading directly from the parlor to the outside to allow for the movement of a casket. INSERT diagram/sketch of aging in place process, bed to funeral in home. In the 1800s, this style of intergenerational living was still common, making aging-in-place a logical model for elder care. And with these domestic structures already classifying women mostly as mothers and caretakers, even in non-multi-generational households, it was regular for daughters to tend to senior family members informally throughout the day, and then return home to their husbands after work.

It was not until the Industrial Revolution in the late nineteenth century, that American women really began to enter the workforce, notably, along with their children as well.[12] The rate

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[10] It is important to note here, that when discussing the typical domestic roles of men and women at this time, that the term *men* refers primarily to cis-hetero white men, and the usage of *women* refers to cis-hetero white women, as during this time, many people of color were either enslaved or under indentured servitude. Enslaved and indentured women of color were forced to work just as the men were, and non-cis, non-hetero individuals were often either hiding their identity from society, or were incapable of living within the normal roles of production during this time due to severe discrimination.

[11] Bradleymountainfarm. "Why Did You Need a Coffin Room?." Bradleymountainfarm. Accessed December 3, 2022, https://bradleymountainfarm.com/barn-blog/f/why-did-you-need-a-coffin-room.

[12] Labor reform did not occur until around the 1930s, so since the industrial revolution until anti-child labor laws were passed, it was common for men, women, and children to all contribute to the household income, often through factory and manufacturing jobs for the latter.

of women holding jobs outside of the home steadily increased until World War II, when it reached a peak as the men went off to fight overseas.[13] With this mechanization of society, came a simultaneous shift marking aging as non-celebratory, because for the first time not only was growing old normal, but dreaded.

In a society that values production above all else, and in which your body is viewed as a vessel for labor,[14] aging means devaluation. Because of this, older Americans were actively pushed out of the workforce, and many industries implemented forced retirement mandates at age sixty-five.[15] Both of these timelines are a direct reflection of the growing production culture that has encapsulated America since the Industrial Revolution. Ironically enough, it was this very advancement of technology and economic growth that even caused life expectancy to increase in the first place. And while labor and social reforms have led the way for retiree protections such as the *Social Security Act* of 1935, American societal roles are still very much driven by capitalism. With no place for these older individuals to work, and with few non-working family

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[12] [cont.] U.S. Bureau of Labor Statistics, "History of child labor in the United States—part 1: little children working : Monthly Labor Review: U.S. Bureau of Labor Statistics," United States Department of Labor

[13] Public Broadcasting Service. "The First Measured Century: Book: Section 2.8." Public Broadcasting Service. Accessed February 14, 2023. https://www.pbs.org/fmc/book/2work8.htm.

[14] Paid labor or otherwise, as one does not want to discount the unpaid labor that many women have done within the home through domestic roles. And for women, with one of their perceived primary functions being to serve as a mother *[yet also as a sexual object to please their husbands; concurrent but separate in function, with opposing physical implications]*, once their vessel of labor *[their body and appearance]* fails to meet the idealized standards of American beauty *[often through age, or pregnancy]*, their societal value as a 'real woman' diminishes.

[15] Samuel, *Aging in America: A cultural history*, 8-12.

members available to care for them through aging-in-place, taking refuge in old age homes became many people's only option.

Prior to the emergence of homes that were strictly for the old, aging individuals who needed care and could not receive familial support were placed into *almshouses,* government run group homes created to shelter and feed those deemed as dependent, including orphans and other-abled individuals. This model was translated from European colonization but fell out of fashion as a suitable place for the elderly towards the end of the nineteenth century. As the idea of specialized geriatric care gained traction, the first *old age homes* emerged. They were run by religious or charity organizations who only charged a small fee for housing and care. When the Social Security Act was passed, it provided government assisted funds only to older individuals who wished to live in one of these old age homes—almshouse residents were prohibited from receiving them. Discovering this, old age homes began to realize that they could privatize their services, and charge residents whatever amount they wanted, because they knew that the government would have to pay for it. While some missionary models continued to exist, for-profit privately run facilities grew increasingly powerful, and with more monetary resources, more favored.

While not exactly the same as nursing homes today, this second iteration of old age homes was the first instance in which aging could be commodified. Privately run business had the consumer demand, and legal right to begin charging residents higher fees. They began

collecting the government assisted funds that were initially put in place to financially protect retired individuals,[16] draining each of their accounts until death.[17]

Further popularizing this trend of isolated aging, was the 1940s-1970s post-war socio-cultural shift towards the nuclear family as the American ideal.[18] The push for a nuclear family not only meant less intergenerational interaction within households, but also resulted in the baby boom. Urging married women to retreat from labor and act as full-time housewives if their husband could afford it,[19] this brief period drove the threshold for expected domestic responsibilities dramatically upwards, leaving women with less and less time. So when social movements of the 1970s-1990s led women to reenter the workforce while still being expected to maintain their positions as the primary caregiver, there simply was not enough time in the day to realistically care for aging parents as well.[20] Working a nine to five in an office, and then a five

[16] This has directly translated into the current implications surrounding a non-socialized healthcare system and the financial options available to cover long-term residential elder care.

[17] Birnstengel, Grace. "How'd We Get Here? The History of Nursing Homes | Next Avenue." Nextavenue. March 5, 2021, https://www.nextavenue.org/history-of-nursing-homes/.

[18] Paul Taylor, Jeffrey Passel, Richard Fry, Richard Morin, Wendy Wang, Gabriel Velasco, and Daniel Dockterman, "The return of the multi-generational family household," *Pew Research Center* 18 (2010).

[19] Ruth Cowan, *More Work for Mother: The Ironies of Household Technology from the Open Hearth to the Microwave* (New York: Basic Books, 1983), 201-216.

[20] Janet Yellen, "The History of Women's Work and Wages and How It Has Created Success for Us All," Brookings, January 6, 2021, https://www.brookings.edu/essay/the-history-of-womens-work-and-wages-and-how-it-has-created-success-for-us-all.

to nine at home became the status quo. With it, the modern popularity of institutionalized aging in nursing homes was born.[21]

"A thirty-five hour week (housework) added to a forty-hour week (paid employment) adds up to a working week that even sweatshops cannot match"

- Ruth Cowan, from More Work for Mother

INSERT graphic timeline including industrial revolution, world wars I and II, the shift in domesticity, and other historical stats, peak use of the term homebound

With a higher demand for care, and more privately run old age homes materializing, the government stepped in and began oversight on the operation. Regulation allowed the government to gain control over how the facilities taking subsidized funds were run. And with the government both dictating and profiting from the construction of these facilities, it acted as a catalyst for the industrialization of the contemporary nursing home. The easiest way to achieve this seemed to be to medicalize the model.

In 1946, the *Hill-Burton Act* was passed, which gave grants to new nursing homes who built their facilities in juncture with hospitals.[22] Because these nursing homes were now considered medical facilities, it meant that the government had the right to oversee both the way they were constructed, and the way they were operated. As regulation expanded, old age homes began to fail the new medical standards that were set to deem them as a proper geriatric

[21] Amfmwv, "What Is a Nursing Home and a Brief History of Nursing Home Origins in the United States," AMFM, Accessed October 6, 2022, https://www.amfmwv.com/blog/what-nursing-home-and-brief-history-nursing-home-origins-united-states.

[22] Birnstengel,

institution. As the ‘outdated’ facilities closed, nursing homes grew increasingly institutionalized, and less home-like in nature.

This trend continued onwards throughout the twentieth century—by the mid-1970s, the number of nursing homes located in the United States grew by one-hundred and forty percent, and their revenues rose over 2,000 percent.[23] This aggressive model of profitability persists today, and as of 2021, the nine highest profiting nursing home companies within the United States made up over twelve percent of the one-hundred and seventy-six billion dollar market. The largest one, *Five Star Senior Living*, had a revenue of five and a half billion dollars, meaning it accounted for a three percent share of the entire industry. While Five Star holds two-hundred and eighty-three facilities across thirty-two states, they only employ 24,700 employees—one and a half percent of the total workers within the market. Four of the other nine big competitors, while less profitable, have more staff, and Senior Sava Care has only slightly less employees, yet accounts for about only a fifth of the revenue of Five Star.[24] This disparity in the revenue to staff ratio sparked an investigation by the Government Accountability Office.

In his State of the Union address of March 2022,[25] President Joe Biden declared that the rate of Wall Street acquisition of nursing homes was alarming. He cited research that suggested private equity ownership in long-term care facilities has shown to produce more negative health

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[23] Birnstengel,

[24] Ariella Sky, "The 10 Largest Nursing Home Companies In The United States" *Zippia* https://www.zippia.com/advice/largest-nursing-home-companies/ (2022)

[25] Notably, in the wake of Covid-19, a viral pandemic that caused mass illness and death within nursing homes at unprecedented numbers.

outcomes for residents, as well as additional costs as compared to other models.[26] Muriel Gillick, licensed physician and professor at the Harvard Medical School, further illustrates this price inequality in her work, *Old and sick in America: the journey through the health care system*. A commonly used strategy by many of these large, for-profit skilled nursing facilities is patient expense inflation through false service 'requirements'. The Office of the Inspector General found that homes were billing patients as needing 'ultra-high' physical therapy on over fifty percent of days. As the most intensive and also most expensive level of therapy that Medicare[27] offers, these ultra-high services were even found to be charged to bedbound, inactive patients who could not possibly complete the physical requirements of said therapy. The cost of this 'ultra-high' therapy is double the price of the lowest level of therapy, and this falsification resulted in over a billion dollars of Medicare funds lost from just 2012 to 2013 alone. Multiple chains, including

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[26] It has been shown that not-for-profit homes, which usually happen to be smaller and more well-staffed than for-profit homes [and also usually ethically or religiously affiliated, such as The Jewish Home of Rochester, New York], tend to have better patient outcomes.

Victoria Knight, "Private Equity Ownership of Nursing Homes Triggers Capitol Hill Questions — And a GAO Probe | Kaiser Health News." *Khn* https://khn.org/news/article/private-equity-ownership-of-nursing-homes-triggers-federal-probe/ (2022)

[27] Commonly mistaken for Medicaid, *Medicare* is government funding provided strictly for the *medical* portion of qualified individuals above age sixty-five. *Medicaid*, on the other hand, is what pays for the long-term *residential* component of nursing home care for those qualified through low income. Both enacted by an amendment to the Social Security Act in 1965, these two financial assistance programs can be charged simultaneously during a nursing home stay. Homes must ensure that for dually eligible patients, all services and fees are itemized and billed to the correct account. This is especially important seeing as Medicaid requires recipients to liquidate all of their assets first before beginning to foot the bill—including social security checks, any valuable possessions, vehicles, and even their homes. Essentially everything that the individual within care and their spouse earns, goes to Medicaid [something that many Americans find grossly unjustified, and unfortunately just another aspect of a non-socialized healthcare system]

Muriel Gillick, *Old and sick in America: the journey through the health care system* (UNC Press Books, 2017), 165-166.

Genesis Healthcare, Kindred Healthcare, Extendicare, and Life Care have already been investigated by or have settled fraud claims with the Department of Justice for this very practice.[28]

So all this time, while both the quantity and price of nursing homes has skyrocketed, the conditions within them have not. Sacrificing the human-focused approach of almshouses and the original old age homes as a transient space to ease into death, nursing homes now have transformed into an industry that instead only focuses on prolonging death. The goal is to maximize financial benefit for as long as possible, meaning keeping patients alive, regardless of the quality of life within their pre-paid bed. With these facilities lacking the same sense of comfort and normalcy that one's traditional home provides, *granny-dumping*, intentional abandonment of a dependent senior by their familial caretaker into the healthcare system,[29] becomes a legitimate fear for many older Americans.

This fear has reason to become heightened, as decades of moving towards a youth focused culture in the United States has caused the sense of value and respect for aging individuals to be lost. Lawrence Samuel, doctor of American studies and author of *Aging in*

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[28] Gillick, *Old and sick in America: the journey through the health care system*, 175-176.

[29] While granny-dumping victims are typically brought to hospital emergency rooms, nursing homes, or other public health-adjacent spaces, they also can be left in extremely unsafe conditions, such as on the street in the cold. The estimated 100,000 individuals who are abandoned in the US each year are also more likely to have dementia, and are left by those who believe they cannot pay for eldercare. When resulting in or presenting a risk for injury or even death, this action can be considered *senicide [the killing of an elderly person; also geronticide]*, and is a legitimate crime.

Robert Hastings, "What is 'granny dumping'? The sad phenomenon of abandoning old people." Inews. October 8, 2020, https://inews.co.uk/news/health/granny-dumping-elderly-people-dementia-roger-curry-286808.

America: A cultural history, illustrates the story of how the once beloved elder has become viewed as a burden on society. He depicts the American perception of aging today as, "a disease that science will one day cure, and in the meantime, signs of aging should be prevented, masked, and treated as a source of shame."[30] With the emergence of this perception came a slew of media driven advertisements and popular culture trends that permeated a youth-centric America. Companies and their marketing team realized that if people started to hate the idea of getting old, then their pockets could profit off of selling the idea of being young. Today, anti-aging creams and exercise routines claiming to 'take years off' of one's waist are so deeply engrained in our culture, that no alarms are raised. But when one realizes that the notion of *aging-backwards* is absurd, and ultimately unhuman, we can recognize how our older Americans have been done a great injustice. Baby boomers have commercialized being, and staying young, and now we are left with a generation of aging persons who have not only been stripped of their identity as an older individual, but who also have little to no knowledge on how to age successfully.[31]

CURRENT IMPLICATIONS [First Age, *realization*]

Even medical professionals seem to be at a loss of words when it comes to describing how to 'successfully age', making it even harder for older patients to seek appropriate advice. Geriatric medicine is relatively infantile as a field specialty, and until 1978, did not exist.[32] Even

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[30] Samuel, *Aging in America: A cultural history*, review excerpt on front cover.

[31] Samuel, 3.

[32] Which is crazy because people have been quite literally, dying forever. Since the dawn of human civilization, people have been aging [of course the life expectancy was much lower, so being *old* usually meant twenty-five or thirty, with forty making one seemingly ancient]. *Why did it take modern western medicine so long to get a grip on this?*

now, the Accreditation Council for Graduate Medical Education[33] fails to recognize gerontology as a major medical specialty. Physicians who are interested in the subject can rather gain a *Certificate of Added Qualifications in Geriatrics* after an examination and a year-long fellowship, or choose to specialize in family medicine, with geriatric medicine or geriatric psychiatry as a sub-specialty.[34] In 2005, there were only 7,128 certified geriatricians, and seeing as this number only rose to 7,279 by 2017,[35] it is hardly likely that the estimated need for 36,000 specialists by 2030 will be met. Of course, not every aging adult needs to visit a geriatric specialist during their routine health checks. But an issue does lay in the fact that generalists, and even primary care physicians specializing in family medicine, feel wholly ill-equipped to deal with older patients. Many providers attribute this lack of preparedness to inadequate education on the topic in medical school, and having the issue further exacerbated during residency with a shortage of placements into skilled nursing or geriatric facilities.[36]

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[33] The regulatory body responsible for accrediting all graduate medical training programs in the United States, including residences, research fellowships, and specialties. Also known as the ACGME, the organization recognizes twenty-eight major specialties, including pediatrics as one of them. *Age-inclusive medical practices have extended to promote specialized care for the earliest stages of life, so why are the latest stages seen as less worthy?*

Acgme. "Specialties." Acgme. Accessed February 20, 2023, https://www.acgme.org/specialties/.

[34] Gillick, *Old and sick in America: the journey through the health care system*, 20.

[35] Equating to approximately twelve [and a half] new certified geriatricians per year. Based on this rate, by the year 2030 there will only be 7,443 certified geriatricians in the entirety of the United States [which is about *one-fifth of the estimated need*].

American Board of Medical Specialties. “2016-2017 ABMS Board Certification Report.” *American Board of Medical Specialties*. http://www.abms.org/media/139572/abms_board _certification_report_2016-17.pdf. (2017).

[36] Gillick, *Old and sick in America: the journey through the health care system*, 20-21.

The injustices done to our aging population by said extreme lack of specialists is only compounded by an additional shortage of available nursing home beds. This has been caused by historically high turnover rates in the long-term care industry. In 2022, it was found that the average skilled nursing facility has to replace over half of its direct care staff each year. [37] This bed shortage means hospitals have had to hold patients that belong in specialized elder care for months, sometimes even years. While already unfair enough on the hospital system, seniors, especially those with dementia, tend to fare a much lower quality of life in these clinical settings as compared to a specialized home. This then reduces any hopeful health outcomes and overall levels of wellbeing.[38]

Given the current atmosphere of aging in the United States, the next generation of older Americans are their caretakers are going to face the challenges brought by the *sandwich generation*. The sandwich generation consists of those responsible for bringing up their own children while also caring for their aging parents. With members of this group typically in their thirties or forties, the already high load of caretaker stress is often heightened by these years being the starting peak of one's career. Brought on by increased life expectancies and an upwards trend in the age that people are choosing to marry and start families at, the first sandwich generation consisted of baby boomers, born between 1946 and 1964. But as baby

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[37] When one hears the concept of a *bed shortage* in long-term care facilities or nursing homes, it typically is actually referring to a *labor shortage*, which is caused by extremely high turnover rates for long-term care staff

The National Consumer Voice for Quality Long-Term Care. "High Staff Turnover: A Job Quality Crisis in Nursing Homes." *theconsumervoice.org* (2022)

[38] Keck, Nina. "Limited nursing home beds force hospitals to keep patients longer : NPR." Npr. December 7, 2022, https://www.npr.org/2022/12/07/1141180491/limited-nursing-home-beds-force-hospitals-to-keep-patients-longer.

boomers age,[39] the burden will shift at an even higher rate to their children—Millennials, born between 1981 and 1996, and some members of Gen Z, born between 1997 and 2012.[40] Based on data from 2020, it is expected that half of today's sixty-five year-olds will require long-term care services before they die, and by 2040, nearly one in four Americans will be age sixty-five or older. By 2035, those aged sixty-five and older are expected to outnumber children for the first time in United States history. The fastest growing group will be those aged eighty-five and up, projected to nearly double from six and half million to twelve million by 2035 and almost triple to nineteen million by 2060.[41] If the age for marriage and pregnancy continues to delay, then this upcoming generation will experience the social phenomenon at unprecedented rates. Older individuals who are cared for by the sandwich generation are more likely to go into skilled care facilities, meaning that the already dire bed shortage is only going to worsen in the next few decades.

Aside from already relatively poor living conditions and severe understaffing in nursing homes, another contemporary problem has arisen for aging adults requiring long-term care. As of

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[39] Currently in 2023, aged fifty-nine to seventy-seven.

[40] Born in 2000 and as a member of Gen Z myself, my parents are both on the end of the baby boomer generation. I know that at least for me [my sister, who is only two years older than I, insists she will be left out of this group], I will more than likely become a part of the next sandwich generation, as will may college aged individuals now. People [especially women] are further pursuing higher education, and waiting longer to get married and start families. While excellent for personal and career development, it does make the Second Age more complicated.

Kim Parker and Eileen Patten, "The Sandwich Generation | Pew Research Center." Pewresearch.org, January 30, 2013, https://www.pewresearch.org/social-trends/2013/01/30/the-sandwich-generation/.

[41] Jonathan Vespa et. al., *Demographic turning points for the United States: Population projections for 2020 to 2060*. (Washington, DC: US Department of Commerce, Economics and Statistics Administration, US Census Bureau, 2018), 1-2.

2022, over six and a half million Americans have been diagnosed with Alzheimer's type dementia—meaning one in three seniors die with it.[42] This increase in instances of neurodegenerative disease is continuing to progress, and by 2050, the number is projected to reach nearly thirteen million.[43]

Dementia is an umbrella term used to describe a particular group of symptoms that present as difficulties with memory, language, problem-solving and other cognitive skills. While there are six diagnosable forms [causes] of dementia, including Parkinson's disease which is frequently mistaken for having just motor symptoms, Alzheimer's disease is the most common.[44] *Alzheimer's disease*, or *Alzheimer's type dementia*, is a neurodegenerative brain disease that is distinguished by the accumulation of protein plaque both onto and into neurons. This plaque causes the death of said neurons, which leads to damaged brain tissue. This is why the brains of decedents with Alzheimer's appear atrophied in autopsies—the tissue is quite literally shrinking in volume.[45] INSERT image of a healthy brain vs a brain with severe Alzheimer's

Alzheimer's is a progressive but ultimately fatal disease, meaning that the brain changes that causes it are thought to begin twenty years or more before symptom onset. This implies that

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[42] Alzheimer's Association, "2022 Alzheimer's disease facts and figures" *Alzheimer's & dementia* 18, no. 4 (2022), 29.

[43] Alzheimer's Association, 19.

[44] Alzheimer's disease accounts for sixty to eighty percent of all dementia occurrences.

[45] Alzheimer's Association, 5.

many of the individuals who will suffer from dementia in the next aging generation already have, or are predisposed for the disease.[46]

Once symptoms do start to appear, the condition is hallmarked by difficulty remembering things. Beginning with short-term memories such as recent conversations or new names, long-term, deeper memory loss does eventually occur in the later stages of progression. A lack of interest in daily life, depression, and transient mood changes are also early stage symptoms. Later onset characteristics include confusion, disorientation, extensive behavioral changes, impaired communication, poor judgment, and perceived distortions of time. Caretakers often note loved ones with dementia 'reverting to' or 'living in' the past, sometimes unintentionally returning to speaking only in their first language, or believing they are of a much younger age.[47]

Ultimately leading to the loss of essential skills such as speaking, swallowing, and walking,[48] Alzheimer's disease is fatal. It was listed as the sixth leading cause of death in the

[46] The way that Alzheimer's disease works is still largely unknown, and so there is no definitive way to determine if this is true. Currently, there are no diagnostic tests for the condition, and the only way to identify its onset is to note when symptoms of dementia first appear.

[47] As a personal anecdote, my grandmother has had Alzheimer's for quite a few years now, and while she fails to recognize any of her grandchildren [and often her children for that matter—although sometimes she refers to my mother as her sister when introducing her to my aunt, who she deems a 'close friend'], she gets excited to see her husband, my grandfather, almost every time. Sometimes she believes he is her brother, or even father, but usually she thinks he is her husband, and no matter which person he occupies her mind as, she understands that he is a very important man in her life. The point is, this reversion back to past life experiences is not always a negative thing, and can often be light-hearted or a source of comedic relief to ease the stress of the reality of the situation.

[48] Alzheimer's Association, 6.

United States in 2019, and the seventh in both 2020 and 2021.[49] Basically, once the ability to walk is lost, patients become bedbound, and once the ability to swallow is lost, risk for death soars. The most commonly identified immediate cause of death due to Alzheimer's disease is *aspiration pneumonia*, which occurs when food or liquid enters the airways or lungs instead of the esophagus, causing acute infection that can lead to respiratory failure.[50] INSERT diagram/figure of the progression and stages of Alzheimer's, reference Alzheimer's Association stages graphic Because the symptoms of Alzheimer's disease can be so wide-ranging, and may take years to fully progress or transform, the creation of spaces that cater to all stages of the condition must be considered.

Also notable, is the data on suspected causes and risk factors for dementia. Understanding who exactly is being placed into these memory care facilities helps inform who exactly the design needs to be built for. While scientists are not entirely sure what causes Alzheimer's disease, it is believed to develop from multiple agents combined, including genetics, lifestyle, and environment. The largest known risk factor is age, doubling every five years after reaching sixty-five. At age eighty-five, one in three individuals have been diagnosed with dementia. Family medical history and genetics are another component, as having a sibling or parent with the disease, or the APOE-e4 gene places one at a strongly elevated risk. Individuals with Down's syndrome are also at a higher genetic risk of developing Alzheimer's, as they possess an extra copy of chromosome twenty-one, which is accountable for the production of the

[49] Again, notably during the peak of the pandemic, when Covid-19 also entered the top ten leading causes of death in the United States.

[50] Alzheimer's Association, 30.

same protein that causes the plaque build-up on neurons in an Alzheimer's affected brain.[51] Certain demographical factors also prove an increased risk. Nearly two thirds of individuals with dementia within the United States are women, and in terms of ethnicity, Hispanic and Black seniors are respectively one-and a half times and twice as likely to develop the disease than White seniors are.[52] While these risk factors cannot be changed,[53] there are secondary environmental and lifestyle considerations that can be influenced. Brain health is tied directly to cardiovascular health, called the *head-heart connection*, so lifestyle choices such as smoking, excessive drinking of alcohol, and inactivity that contribute to the conditions of obesity, diabetes, and high blood pressure, all put one at a greater risk. Researchers suggest following an active lifestyle, walking regularly, and eating a heart healthy diet[54] to help curb the possibility of developing dementia. Additional, modifiable factors include:

Education and Educational Opportunities-

People with more years of formal education are at a lower risk for developing Alzheimer's disease than those without. While the underlying correlation is unclear, some researchers believe that education builds *cognitive reserve*, the brain's ability to make flexible and efficient use of neuronal networks despite brain changes. Having an intellectually stimulating job and participating in other mentally engaging activities can also help build cognitive reserve.

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[51] Alzheimer's Association, 13-14.

[52] Alzheimer's Association, 24-25.

[53] While gender can be reassigned through personal identification and medical treatment, it is too new of an emerging science to have any correlations linked between being transgender and developing Alzheimer's. Transgender women may not have the same risk factor as cisgender women do, and the same goes for transgender compared to cisgender men.

[54] Emphasizing the consumption of fruits, vegetables, whole grains, fish, chicken, nuts, legumes and healthy fats such as olive oil while limiting saturated fats, red meat and sugar, some examples of heart-healthy diets are the Mediterranean, DASH (Dietary Approaches to Stop Hypertension) and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets.

Social and Cognitive Engagement-

Similarly, researchers suggest that remaining socially and mentally active throughout life supports brain health and might also help build cognitive reserve, reducing the risk for developing dementia.

Head Injury-

When resulting in a traumatic brain injury, a head injury poses a threat for the onset of Alzheimer's in the future. Medical professionals advise protecting one's brain by always using a seat belt, wearing a helmet when participating in sports, and 'fall-proofing' one's home later in life.

Air Pollution-

There is new evidence suggesting that long-term exposure to fine particulate air pollution may be related to dementia risk. Higher levels of exposure are associated with worsened cognitive decline, and the incident of pulmonary disease, which is also a risk factor for Alzheimer's.[55]

By beginning to understand these risk factors, and designing public spaces that promote prevention, built interventions can start to address the progression of Alzheimer's type dementia on multiple levels. With additional research to be done on the disease, there are more possibilities for growth within care environments.

THE THESIS [Second Age, *getting stuff done*]

The rise of Alzheimer's disease in American society is a contemporary issue that has yet to be fully architecturally resolved, and when placed within the vacuum of the historical creation of nursing homes in the United States, the aging population has been done a great injustice. Government, business, and healthcare entities have swooped in to commodify the aging process, profiting off the lack of *place* that older Americans experience in a society that is not built for them. It is because these entities have created the current model of nursing homes in a fashion that only benefits them through monetary gains, that the existing standard is so bad. In other

[55] Alzheimer's Association, 15-17.

words, we know that the nursing home industry and those running it are winning, but only on behalf of the seniors within them losing, especially those with dementia. This solidifies the need for a reexamination of the typology of memory care homes in America. Specialized care requires specialized space, and this thesis seeks to define that. When rooted in thoughtful design through the concepts of autonomy, community, and nostalgia, these facilities can promote normalcy and create a dignified environment for residents living there.

Cultures with different attitudes towards intergenerational living, and aging in general, have begun to offer this nobler model of geriatric care. The Netherlands opened *De Hogeweyk* in 2009, [56] the first built prototype for the concept of a *dementia village*, a nursing home campus that intentionally mimics a real village through a combination of residential, commercial, and 'public' buildings. [57] Camouflage is the key element that allows dementia villages to work—while still technically a medical facility, they appear to have no buildings dedicated to health. This allows residents to feel as though they are living within a quaint town, disguising the truth of it actually being a nursing home. This idea of blissful ignorance is then heightened by an aspect of nostalgia. INSERT images of nostalgic town setup at hogeway

It is important to note however, that while residents may believe they are living in a quiet 1950's era village with access to shops, green spaces, weekly live events in public gathering areas, and a house of their own, the reality is still merely a crafted utopia. Residents are still patients, and patients do not have free will to leave the premises. In this way, the aspect of

[56] *De Hogeweyk*, or *The Hogeway* [English], was designed by Dutch architects Molenaar&Bol&VanDillen [MBVD] which became Buro Kade Architects in 2018

[57] Annmarie Adams and Sally Chivers, "Deception and Design: The Rise of the Dementia Village," *E-flux Architecture* (2021)

security is not compromised with an attempt for autonomy. The bus stop that 'allows' residents to sit and wait for a ride never has any buses, and all of the 'private' homes that are shared between six patients according to lifestyle choices are under surveillance 24/7. Somewhat *Truman Show-esque,*[58] this model leans into the delusion that residents with dementia already live with every day. Also known as validation therapy, this method of treatment fosters connection with dementia patients by sharing their experience of the world. While each moment may entail a different perceived time or place, the whole notion rests on being present with the individual as they move through transitory coherence. The Hogeweyk uses validation therapy on a tangible level, world-building a nostalgic town for its residents that does not exist. Through this deception, the sterilized feel of a clinical facility is purposefully reversed.

> Architectural historian and joint professor of Architecture and Medicine at McGill University, Annmarie Adams, eloquently describes it:
>
> The goal of building a caring environment is a direct counterpoint to the uncaring institution, the traditional nursing home, and its long list of much maligned architectural features—the car-dependent entrance, double-loaded and crowded corridors, identical rooms, enclosed courtyards—and its human counterparts—caregivers dressed in white sporting highly visible medical technologies. The caring village is purposefully anti-medical. That is, medical care is disguised. Just as the architecture is that of assisted

[58] A 1998 film starring Jim Carrey as a thirty-year-old insurance salesman who eventually discovers his entire life is actually a television show, that even members of his family are actors, and that he is never allowed to leave. *Being John Malkovich*, a film that came out a year later depicts a similar type of offbeat surveillance. Craig, a struggling puppeteer takes an office job and accidentally discovers a portal that leads directly into the mind of renowned actor John Malkovich. Eventually, Malkovich falls into despair over his lost sense of control of his own mind, something which is extremely relatable for those with dementia. Sometimes patients may be mentally occupied by an earlier version of themselves, without even realizing it. The difference between the film and real life individuals with Alzheimer's however, is that best practice encourages 'playing along' with the false perceptions. A common example of this is not correcting someone with dementia when they say their late spouse, or parent is still alive. If they find out said person is dead and did not believe so, they will mourn all over again. Dementia literally eats away memories stored in neural connections, so if they are gone, forced 'remembrance' will just make the event occur as a new memory, never seen before.

> living but dressed up as a village, in a caring village, the staff are trained nurses but dressed up as cashiers.[59]

While there is some controversy over the ethicality surrounding treating a disorder characterized by losing touch with reality with more delusion, validation therapy is still considered the best practice. Currently, medical practitioners view dementia as a largely untreatable, irreversible condition. And when a disease cannot be cured, normalization of life for those suffering from it is considered to be the best option.[60]

The emergence of the dementia village can be traced back to two key trends in healthcare architecture—one, the trope of the 'village' communal setting as healing, and two, the steady adoption of hospitality design into medical settings. Hospitals and long-term care facilities have increasingly grown to look more and more like malls,[61] airports, or hotels over the past forty years. The answer for this trend lies in wanting improve public opinion of medical entities in general. [62] With nicer rooms, single patient bays offering better privacy, and colorfully thought out wall protection details or flooring patterns increasing wayfinding ability, medical buildings may seem slightly less scary. And when the fear of, or distaste for practitioners and clinical

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[59] Annmarie Adams, "Deception and Design: The Rise of the Dementia Village"

[60] Annmarie Adams,

[61] Medical campuses or large medical facilities have actually shown to be a great adaptive reuse of dying or vacant malls in recent years. Few other programs require the same spatial and parking requirements as these two do, and it is much cheaper for healthcare systems to buy and renovate an existing box store than it is to build new from the ground up. A great example of this is the new *University of Rochester Medicine Orthopaedics and Physical Performance Center*, built into Rochester New York's Marketplace Mall: https://www.urmc.rochester.edu/orthopaedics-center.aspx

[62] Annmarie Adams,

settings is reduced, people are more likely to want to go to the doctor when they need health-related help.

The idea of the 'village' as a healing setting is slightly more nuanced when discussing design for wellness outcomes. While these villages are considered relatively 'nice' places to live, and many family members sleep better at night knowing their loved one is residing in a dementia utopia, these villages are less about community then they are about containment. In a true communal setting, social interactions with other groups would be built in, not forged or enacted by paid nurses. The healing power that comes from community is based on the notion that genuine human connection fosters wellbeing and a sense of purpose in one's life. With the genuine aspect of these interactions removed, it becomes harder to understand if the premise of dementia villages works. Perhaps the ideal model of a dementia village would look more like a community resource, as opposed to a gated community.[63]

One facility, *Dementia village Wiedlisbach*, designed by GWJ Architektur, has taken the first steps towards this concept. Their site, while relatively detached from any real neighbors, is directly adjacent to a daycare, and multiple hiking trails. All within the campus, Wiedlisbach offers a publicly accessible café, hairdresser, a modest supermarket, and an intimate music venue. The goal of these amenities is increased interaction with staff and patrons of the daycare, thru-hikers, and surrounding locals.[64] Other Hogeweyk type nursing homes have been built in

[63] The question still lies however, *how do you keep residents in, without barring others out?*

[64] GWJ, "Dementia Village Wiedlisbach - GWJ Architecture," GWJ, https://www.gwj.ch/projekte/2019-p-wiedlisbach-demenz-architektur.

Germany, Italy, and in the United Kingdom, but Switzerland's Wiedlisbach has been the first to really the push boundaries against resident containment and gated isolation.

So while the dementia village has flourished across Western Europe, its model struggles within the United States. Explained in part by the nation's economic underpinnings of a non-socialized healthcare system,[65] a lack of awareness surrounding successful implementation of unconventional design solutions may also be a culprit. This is illustrated at *Glenner Town Square*,[66] a senior daycare developed in Chula Vista, California, that imitates the sentimental aesthetics of *The Hogeweyk*, but fails to provide the specialized care that dementia patients truly need. INSERT COMPARISON IMAGES OF ALL

There are however, other alternative nursing home models in America that have attempted to better the standards of elder and memory care. Wellspring Innovative Solutions is a group of eleven nonprofit nursing homes in Wisconsin that banded together in 1994 to analyze and improve the standard of long-term geriatric care. Known as the *Wellspring project*, the team believed that radical culture change would be required to make aging in American nursing homes a positive process for older individuals. The best way they thought to do this was by making continuous small improvements, on all levels of care, based on both patient and staff input. Resulting in lower staff turnover rates, better performance on state reviews, patient noted

[65] Josh Planos, "The Dutch Village Where Everyone Has Dementia. The town of Hogeway, outside Amsterdam, is a Truman Show-style nursing home," *The Atlantic* (2014).

[66] Kendra Gillio, "Enhancing Engagement in Older Adults with Alzheimer's Disease at a Reminiscence Therapy Adult Day Center," (2020).

improved quality of life, and better communication between staff and patients overall, the project acted as a catalyst for other initiatives to organize.[67]

Around the same time, Dr. Bill Thomas, an iconoclastic geriatrician decided to start another alternative model for nursing homes after witnessing firsthand as a provider how bad conditions really were. He called his model the *Eden Alternative*, and the nursing homes partnered with it seek to alleviate depression and loneliness through the power of nature. Originally bringing in plants and animals to help boost resident morale, the movement has since expanded. Combining this theory with the Wellspring model, the *Pioneer Network* was founded as a nonprofit organization in 1997 to promote aging in homes that makes life humane and meaningful. Focusing on home-like structures, living units comprise of no more than fifteen residents. The model also swapped centralized nursing stations with centralized kitchens and dining rooms that act as communal spaces for residents to socialize and participate in the activities of normal life, like cooking or doing chores. Nurses and care providers work together to care for each unit, and include patients in decision-making about daily routines.[68]

With Pioneer Network affiliated homes producing mixed results, Thomas revised the plan and came up with a third iteration, the *Green House* model. While keeping the principles of patient-centric care, staff engagement, and social interaction between residents, Green House homes have even smaller, more familial like units, housing no more than ten patients.[69] Now consisting of over one-hundred and eighty facilities across twenty-eight states, this model seems

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[67] Gillick, *Old and sick in America: the journey through the health care system*, 178-179.
[68] Gillick, 179.

[69] In comparison, De Hogeweyk units comprise of six residents each.

to be the most effective alternative to traditional medicalized nursing homes that is available within the United States.[70] INSERT comparison graphic of each model type

Learning from these nursing home models, and the contextual factors surrounding modern day American memory care, the architectural synthesis that needs to be explored must be both premeditated and pluralistic in nature. Somewhere between an almshouse and a dementia village, the baseline considerations for a solution must fit within the current cultural context of aging with dementia in the United States. The idea of a non-socialized healthcare system and its historical origins, the ongoing bed shortage, and general lack of knowledge surrounding the treatment of Alzheimer's must all be accounted for. Additionally, nostalgic influence ages with each generation, meaning routine renovations must be carefully phased and planned in a way that does not disrupt residents. All things considered, the synthesis is more than just a memory care facility, it is a campus complex operating on the core principles of nostalgia, neighborhood interaction, intergenerationality, and autonomy—a multi-modal intervention that addresses the progression of dementia via the built environment. This thesis proposes the new complex to be located in Rochester, New York, on a site that reclaims a sense of normalcy for residents and provides for a historically underserved, at risk community.

THE SITE [Third Age, *activity and fulfillment*]

When selecting a site, multiple criteria were selected. Appropriate site requirements include:

- Accessibility

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[70] Gillick, 179-180.

accessible by public transport, excessive handicap and accessible parking, highly accessible entrances, and accessible to service vehicles and utilities

- Room for future expansion
- Close proximity to outpatient specialized medical offices for patient appointments
- Two acres minimum lot size

  needs to be big enough to host a fully ground level, one-story building

- Allowable zoning and permit for new construction
- Ambiance

  needs to be relatively peaceful and quiet, have access to nature, lots of natural lighting

- Nighttime lighting implemented for safety purposes
- Needs to be by a local aging population
- Climate and conditions

  needs to have suitable soil for building on, needs to be relatively flat making it accessible without having to extensively regrade the site, and building needs to be accommodative of the existing climate and natural environment

Additional, desired conditions include:

- Close proximity to a school, preschool, or daycare, possibly shares the site with it
- Close proximity to a large ‘sandwich generation’
- Should have fake blue bus stops and benches (to prevent escaping)
- Not be directly next to heavy traffic in case there is an escape
- Part of a walkable district in the larger regional context
- Lot development should clear as few trees as possible
- Lot should be close to local construction material sources
- Should have a population that is expected to either maintain rates of aging, or increase over the next years
- Tied into the local urban or suburban fabric of the region
- Incorporate local plant species
- Promote access to public ‘safe’ recreational activities, such as walking paths or an intergenerational playground

With all of this in mind, the selected site is 20 kay Terrace, in Rochester, New York. It meets all of the requirements and many desired conditions, making it an excellent fit. INSERT image, site analysis The site is located within the Historic Edgerton District, which has become extremely health vulnerable due to discriminatory redlining practices. Initially graded as a 'C' on the four tier mortgage security scale by the Home Owners Loan Corporation during the 1930s, this neighborhood continues to have adverse health outcomes today. Due to its ranking over 90 years ago as 'definitely declining', Edgerton is now among the top 1% of at risk Rochester neighborhoods in the Center for Disease Control's social vulnerability score, which indicates a community's capacity to prepare for, respond to, and recover from regional health threats, such as a large scale increase in dementia. [71] INSERT graphics on historic redlining to current health vulnerability. Compounding this effect, is the fact that the district also has a highly at-risk demographic for developing Alzheimer's in the first place. INSERT diagram on dementia risk factor stats Through the careful selection of this site, thoughtful design work can finally materialize.

THE SYNTHESIS [Fourth Age, *dependency and frailty*]

Thoughtful design of memory care facilities begins first with sociopsychological foundations, and then exhibits architectural interventions. The built environment acts as the ultimate mediator of experience, which is why it is crucial to emulate the spaces of life that residents experienced prior to the onset of their condition—because for them, life before dementia is their state of normalcy. Sense of normalcy may look different for everyone based on

[71] Dsl. "Not Even Past." Dsl. n.d.,https://dsl.richmond.edu/socialvulnerability/map/#loc=14/43.177 /- 77.649&city=rochester-ny&tract=36055002300.

what their past life was however, therefore, customization and personalization of private spaces is key. Additionally, interventions such as domestic skills stations are vital in helping to ground patients in regular purpose driven routines, reducing distortions in perception of place and time. Nostalgia driven by the everyday familiarities of human life can actually facilitate recollection.[72]

It is this concept of neural preservation as a means of increasing quality of life in the milieu of an American approach to aging and memory care, that must evolve within an architectural framework. Such synthesis will instigate questions at the nexus of neuropsychological and design perspectives. *Can spatial interventions trigger nostalgia that helps preserve neuronal networks in patients with dementia? What role does a spatially forged sense of community play on perceived quality of life?* Sitting alone, bored, and disconnected from normal worldly interactions in a sterile room is not what life with dementia should look like, and this thesis seeks to change that.

AFTERWORD [death]

Future Synthesis TBD (not finished with thesis therefore no final synthesis) Explain that this can be implemented on multiple sites and context, serves as a new typology for the future and also a catalyst for discussion and cultural or systemic change

[72] Sanda Ismail, Gary Christopher, Emily Dodd, Tim Wildschut, Constantine Sedikides, Tom A. Ingram, Roy W. Jones, Krist A. Noonan, Danielle Tingley, and Richard Cheston, "Psychological and mnemonic benefits of nostalgia for people with dementia," *Journal of Alzheimer's Disease* 65, no. 4 (2018): 1327-1344.

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