



AMERICAN UNIVERSITY | WASHINGTON COLLEGE OF LAW

# HEALTH LAW & POLICY BRIEF

VOLUME 19 • ISSUE 1 • FALL 2024

## ARTICLES

ALCOHOL AND CANCER: A NEW LITIGATION STRATEGY  
AGAINST LARGE PRODUCERS..... *Andrew Swanson*

WE SHOULDN'T FORGET: FINANCIAL AND ETHICAL BARRIERS  
TO ACCESSING LONG-TERM CARE FOR PATIENTS WITH  
ALZHEIMER'S DISEASE..... *Taylor Campbell*

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WE SHOULDN'T FORGET: FINANCIAL AND ETHICAL BARRIERS TO ACCESSING LONG-TERM CARE FOR PATIENTS WITH ALZHEIMER'S DISEASE

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# LETTER FROM THE EDITORS

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Dear Reader:

On behalf of the Editorial Board and Staff, we proudly present Volume 19, Issue 1 of the *Health Law & Policy Brief*. Since its formation in 2007, the Brief has published articles on an array of topics in health law, food and drug law, and emerging health technologies. This issue includes two impactful articles: the first advocates for robust litigation and regulatory measures to address public health concerns related to the U.S. alcohol industry, while the second discusses strategies to overcome financial and ethical barriers to equitable Alzheimer's care. Both articles highlight critical healthcare challenges and propose solutions that could significantly improve the American healthcare system.

Our first article, by Andrew Swanson, delves into the overlooked connection between alcohol consumption and cancer, exposing how Big Alcohol has systematically suppressed public awareness of these risks. Mr. Swanson draws compelling parallels to the tobacco and opioid litigation landscapes, arguing that similar strategies could hold the alcohol industry accountable through both individual lawsuits and state-led *parens patriae* actions. Mr. Swanson's analysis highlights the urgency and burgeoning potential for public health litigation to drive change in consumer safety and regulatory policy.

Our second article, by Taylor McGee Campbell, examines the financial and ethical barriers that prevent equitable access to long-term care for individuals with Alzheimer's disease. Ms. Campbell provides a poignant critique of systemic failures in U.S. healthcare, highlighting disparities in care quality, widespread abuse in nursing facilities, and the urgent need for reforms to protect one of society's most vulnerable populations. She concludes that meaningful progress will require both policy innovation and a societal commitment to ensuring that all individuals, regardless of financial means, receive the dignified and compassionate care they deserve.

We would like to thank the authors for their insight, creativity, and cooperation in producing these pieces. We would also like to thank the *Health Law & Policy Brief's* article editors and staff members who worked so diligently on this issue.

To all our readers, we hope you enjoy this issue, that the never-ending complexities of this area of law inspire your own scholarship, and that you continue to anticipate and scrutinize the inevitable challenges that our healthcare system continues to withstand.

Sincerely,

Giulia Pastore  
*Editor-in-Chief*

Guy Cheatham  
*Executive Editor*

# ALCOHOL AND CANCER: A NEW LITIGATION STRATEGY AGAINST BIG PRODUCERS

*Andrew Swanson\**

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## ABSTRACT

For decades, public health experts have raised alarms about cancer risks associated with moderate to excessive alcohol use.<sup>1</sup> Despite overwhelming evidence demonstrating a causal relationship between alcohol use and various types of cancer, regulators in most Western countries have failed to take steps to mitigate these harms.<sup>2</sup> As a result of regulators' inaction and the alcohol industry's "self-regulation," public understanding of the cancer-related risks associated with drinking alcohol is limited.<sup>3</sup>

While litigation strategies have effectively driven policy changes and public health gains in areas like tobacco and opioids,<sup>4</sup> similar efforts against the alcohol industry have largely failed.<sup>5</sup> Longstanding jurisprudence in American courts disfavors product liability actions against alcohol manufacturers for harms related to addiction<sup>6</sup> and alcohol misuse; this is in part because the risk of experiencing harm from alcohol use is widely understood so drinkers assume some level of blame for taking the risk.<sup>7</sup> Consequently, we have not yet seen any effective wide-scale public health policy efforts targeting alcohol. However, evidence revealing Big Alcohol's practices to limit consumer understanding of alcohol related cancer risks is mounting, and with that comes an increased likelihood of public health efforts to reduce harms, including litigation.<sup>8</sup>

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<sup>1</sup> *Alcohol increases cancer risk, but don't trust the booze industry to give you the facts straight*, CANCER COUNCIL AUSTRALIA. (Sept. 8, 2017), <https://www.cancer.org.au/blog/alcohol-increases-cancer-risk-but-dont-trust-the-booze-industry-to-give-you-the-facts-straight>.

<sup>2</sup> Theresa J. Hydes et al., Exploring the Gap in the Public's Understanding of the Links Between Alcohol and Cancer, 20(1) CLINICAL MED. 4 (2020).

<sup>3</sup> *Id.*

<sup>4</sup> See *Cipollone v. Liggett Grp.*, 505 U.S. 504 (1992); Walter J. Jones & Gerard A. Silvestri, The Master Settlement Agreement and its Impact on Tobacco Use 10 years Later: Lessons for Physicians About Health Policy Making, 137(3) CHEST 692, 692 (2010).

<sup>5</sup> Clay Campbell, Liability of Alcoholic Beverage Manufacturers: No Longer a Pink Elephant, 31 WILLIAM & MARY L. REV., 157, 157-58 (1989).

<sup>6</sup> In this paper I use the term "addiction" instead of DSM-5 preferred phrases like "alcohol use disorder" and "opioid use disorder." This is primarily to make the paper more easily understandable and actionable to people who may not be familiar with medical terminology. As an advocate, I have found that the broader public responds more affirmatively to the word addiction as it is something that they likely have some connection to.

<sup>7</sup> Campbell, *supra* note 4, at 158-59.

<sup>8</sup> This paper often refers to Big Tobacco and Big Alcohol. Big Tobacco includes the four largest tobacco companies—Philip Morris International, British American Tobacco, Japan Tobacco International and Imperial Brands—as well RJ Reynolds and Liggett & Myers Tobacco Co. Big

As a result of settled litigation against the large tobacco companies in the 1990s, known as the Master Settlement, the public has gained access to millions of internal corporate documents from several major players in the tobacco industry.<sup>9</sup> Researchers poring through those documents have encountered something unexpected—direct links between Big Tobacco and large alcohol manufacturers, including the existence of secret coalitions between the two industries to advance policy agendas and campaigns paid for by the alcohol industry to thwart anti-smoking efforts.<sup>10</sup> These documents prompt the question of whether the alcohol industry was, to any degree, actively suppressing public health information concerning the cancer risks associated with moderate to excessive alcohol consumption in the same way Big Tobacco hid the link between smoking and cancer.

Qualitative research on millions of Master Settlement documents reveals that the alcohol industry was (1) acutely aware of cancer risks associated with alcohol as far back as the 1960s, and was (2) using the Big Tobacco playbook to suppress public awareness of those risks, including spreading misleading or outright false health information through third-party sources that were not easily linked back to the alcohol industry.<sup>11</sup> Arguably, the alcohol industry has so successfully suppressed public understanding of the dangers of alcohol consumption that it has potentially exposed itself to product liability suits from a new class of victims—cancer patients.

This article makes the case that, as a direct result of the alcohol industry's highly successful suppression of public awareness of the alcohol-cancer connection, the industry has exposed itself to product liability claims from cancer victims and actions from states' attorneys general under the *parens patriae* doctrine. To support this contention, this article examines the outsized risks of certain types of cancers from alcohol use and the highly effective efforts of alcohol manufacturers to suppress public awareness of those risks. By examining the trajectory of tobacco and opioid litigation, we see that the tide of

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Alcohol refers to large-scale alcohol producers including but not limited to Bacardi Limited, Anheuser-Busch InBev, Diageo, and Asahi Group.

<sup>9</sup> See TOBACCO INDUSTRY DOCUMENTS, <https://www.industrydocuments.ucsf.edu/tobacco/> (last visited Oct. 22, 2024) (providing 14 million documents created by tobacco companies about their advertising, manufacturing, marketing, scientific research and political activities).

<sup>10</sup> Nan Jiang & Pamela Ling, Vested Interests in Addiction Research and Policy: Alliance between tobacco and alcohol industries to shape public policy, 108(5) ADDICTION, 852, 852-53 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3689428/>.

<sup>11</sup> See Mark Petticrew, et al., *How alcohol industry organisations mislead the public about alcohol and cancer*, 37 DRUG & ALCOHOL REV. 293, 297-99 (2018), <https://onlinelibrary.wiley.com/doi/full/10.1111/dar.12596> (addressing the three specific strategies the alcohol industry uses to mislead the public about alcohol and cancer).

accountability is beginning to turn against large-scale alcohol manufacturers and a day of reckoning is coming.

## I. WHY WE SHOULD CARE

### A. Alcohol-Caused Cancer is Widespread

Alcohol use is the third leading preventable cause of cancer behind obesity and tobacco use, and 4% of all new cancer cases in 2020 were attributable to alcohol.<sup>12</sup> At the global level, alcohol caused 6.3 million cancer cases and 3.3 million deaths in 2020.<sup>13</sup> Comparatively, roughly 125,000 deaths worldwide were attributable to opioids in 2019.<sup>14</sup> The World Health Organization (WHO) classified alcoholic beverages as a Group 1 carcinogen 35 years ago.<sup>15</sup> Group 1 carcinogens are the highest-risk carcinogens because they are known to cause cancer in humans.<sup>16</sup>

National figures fare no better. According to the American Cancer Society, alcohol use is a leading preventable risk factor for cancer and contributes to 6% of all cancers and 4% of all cancer deaths in the United States.<sup>17</sup> A 2013 study in the American Journal of Public Health showed that the majority (56-66%) of alcohol-attributable cancer deaths among women were the result of alcohol-related breast cancer.<sup>18</sup> Among men, the majority (53-71%) of deaths

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<sup>12</sup> Isabella Cueto & J. Emory Parker, *By the numbers: America's alcohol-related health problems are rising fast*, STAT (June 27, 2024), [https://www.statnews.com/2024/06/27/alcohol-related-health-problems-rise/#:~:text=Cancer,it%20courses%20through%20the%20body;HarrietRumgay,et%20al.,Globalburdenofcancerin2020attributabletoalcoholconsumption:apopulation-basedstudy,22LANCETONCOLOGY1071,1071\(2021\),https://www.thelancet.com/article/S1470-2045\(21\)00279-5/fulltext](https://www.statnews.com/2024/06/27/alcohol-related-health-problems-rise/#:~:text=Cancer,it%20courses%20through%20the%20body;HarrietRumgay,et%20al.,Globalburdenofcancerin2020attributabletoalcoholconsumption:apopulation-basedstudy,22LANCETONCOLOGY1071,1071(2021),https://www.thelancet.com/article/S1470-2045(21)00279-5/fulltext).

<sup>13</sup> Rumgay, *supra* note 12, at 1071.

<sup>14</sup> OPIOID OVERDOSE KEY FACTS, WHO (Aug. 2023), <https://www.who.int/news-room/fact-sheets/detail/opioid-overdose#:~:text=Worldwide%2C%20about%20600%20000%20deaths,of%20opioid%20overdose%20in%202019> [hereinafter WHO FACT SHEET].

<sup>15</sup> Tim Stockwell, et al., *Cancer Warning Labels on Alcohol Containers: A Consumer's Right to Know, a Government's Responsibility to Inform, and an Industry's Power to Thwart*, 81(2) J. STUDIES ON ALCOHOL & DRUGS 284, 284 (2020), <https://www.jsad.com/doi/10.15288/jsad.2020.81.284>.

<sup>16</sup> *See id.* (stating WHO's recognition that alcohol-related cancers contributed significantly to 3 million deaths).

<sup>17</sup> *Alcohol Use and Cancer*, AM. CANCER SOC'Y (June 9, 2020), <https://www.cancer.org/cancer/risk-prevention/diet-physical-activity/alcohol-use-and-cancer.html>.

<sup>18</sup> David E. Nelson, et al., *Alcohol-Attributable Cancer Deaths and Years of Potential Life Lost in the United States*, 103 AM. J. PUB. HEALTH 641, 641 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3673233/>.

resulted from upper airway and esophageal cancer.<sup>19</sup>

To date, researchers have established causal relationships between alcohol consumption and oral, pharynx, larynx, esophagus, liver, colon, rectum, and breast cancers.<sup>20</sup> Further evidence suggests a person's genetic ability to metabolize alcohol may play a role in the likelihood of contracting alcohol-caused cancer.<sup>21</sup>

### *B. Light to Moderate Drinking Still Increases the Risk of Cancer*

Moderate drinkers, while experiencing significantly lower risks of cancer compared to excessive drinkers, still face an 80% greater likelihood of contracting head and neck cancers compared to those who do not drink.<sup>22</sup> Even those who are considered light drinkers (no more than one drink per day) experience a 30% increase in risk of esophageal cancer compared to those who do not drink at all.<sup>23</sup> It is important to note that alcohol is a carcinogenic substance and consuming any amount creates risks. Researchers have proven time and again that—despite industry-funded messaging to the contrary—no level of alcohol consumption is considered healthy or safe.<sup>24</sup>

### *C. Public Awareness of Alcohol-Related Cancer Remains Low in the United States*

In 2017 the American Institute for Cancer Research conducted a Cancer Risk Awareness Survey, finding that, while 93% of respondents were aware of the risks of contracting cancer associated with tobacco use, only 39% of respondents were aware of cancer risks associated with alcohol use.<sup>25</sup> There are also significant disparities in the public's understanding of how different types of alcohol affect them. A 2023 study analyzing data from a National Health Survey found that adult respondents' understanding of alcohol-related cancer risks varied

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<sup>19</sup> *Id.*

<sup>20</sup> Paolo Boffetta & Mia Hashibe, *Alcohol and Cancer*, 7(2) LANCET ONCOLOGY 149, 149 (2006).

<sup>21</sup> *Id.* at 152.

<sup>22</sup> *Alcohol and Cancer Risk Fact Sheet*, NAT'L CANCER INST. (July 14, 2021), [https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol/alcohol-fact-sheet#:~:text=Moderate%20drinkers%20have%201.8%2Dfold,cancers%20\(4%2C%209\).](https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol/alcohol-fact-sheet#:~:text=Moderate%20drinkers%20have%201.8%2Dfold,cancers%20(4%2C%209).)

<sup>23</sup> *Id.*

<sup>24</sup> See Benjamin O. Anderson, et al., Comment, *Health and cancer risks associated with low levels of alcohol consumption*, 8 LANCET ONCOLOGY e6 (2023), [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(22\)00317-6/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(22)00317-6/fulltext); Petticrew, *supra* note 11, at 297.

<sup>25</sup> *2017 AICR Cancer Risk Awareness Survey Report 1*, 5, AM. INST. FOR CANCER RSCH. (2017), [https://www.aicr.org/assets/docs/pdf/reports/AICR%20Cancer%20Awareness%20Report%202017\\_jan17%202017.pdf](https://www.aicr.org/assets/docs/pdf/reports/AICR%20Cancer%20Awareness%20Report%202017_jan17%202017.pdf).

by the type of alcohol<sup>26</sup>—31.2% of respondents believed there was a link between spirits and cancer, but only 20.3% believed there was a link between wine consumption and cancer.<sup>27</sup> Further, 10.3% of respondents erroneously believed that wine consumption reduced the risk of cancer.<sup>28</sup> The reasons for suppressed public knowledge of cancer risks and misguided public beliefs in debunked health benefits of alcohol consumption are explored later in this paper.

#### *D. Americans are Drinking More Since the Onset of the COVID-19 Pandemic*

Early studies analyzing alcohol use during the COVID-19 pandemic suggest an alarming increase in alcohol consumption across American demographics.<sup>29</sup> In the months following the first COVID-19 lockdown, respondents in one study reported a 29% increase in their drinking.<sup>30</sup> Notably, women appear to have experienced the largest increase in alcohol use.<sup>31</sup> The RAND Corporation<sup>32</sup> found that heavy drinking among women increased by 41% following the onset of the COVID-19 pandemic whereas heavy drinking among men only increased by about 7%.<sup>33</sup> Organizations that track industry data have shown similar trends.<sup>34</sup> For the week ending March 21, 2020 (just weeks into the COVID-19 pandemic), Nielsen reported a 54% increase in national alcohol sales

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<sup>26</sup> Andrew B. Seidenberg et al., Do Beliefs about Alcohol and Cancer Risk Vary by Alcoholic Beverage Type and Heart Disease Risk Beliefs?, 32(1) *CANCER EPIDEMIOLOGICAL BIOMARKERS & PREVENTION* 46, 47–48 (2023), <https://pubmed.ncbi.nlm.nih.gov/36453075/>.

<sup>27</sup> *Id.*

<sup>28</sup> *Id.*

<sup>29</sup> Carolina Barbosa, et al., *Alcohol Consumption in Response to the COVID-19 Pandemic in the United States*, 15(4) *J. OF ADDICTION MED.* 341, 341 (2021), <https://pubmed.ncbi.nlm.nih.gov/33105169/>.

<sup>30</sup> *Id.*

<sup>31</sup> *Id.* at 342-43.

<sup>32</sup> See *About RAND*, RAND CORP. (2024), <https://www.rand.org/about.html> (giving an overview of the RAND Corporation’s website, where the organization describes itself as a “nonpartisan. . . nonprofit. . . research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous.”).

<sup>33</sup> Michael S. Pollard, et al., *Changes in Adult Alcohol Use and Consequences During the COVID-19 Pandemic in the US*, RAND CORP. (2020), [https://www.rand.org/pubs/external\\_publications/EP68312.html](https://www.rand.org/pubs/external_publications/EP68312.html).

<sup>34</sup> *Rebalancing the ‘COVID-19 effect’ on alcohol sales*, NIELSEN CONSUMER (May 7, 2020), <https://nielseniq.com/global/en/insights/analysis/2020/rebalancing-the-covid-19-effect-on-alcohol-sales/>; *Alcohol Does Not Protect Against COVID-19 and Access Should be Restricted During Lockdown*, WHO, <https://www.emro.who.int/mnh/news/alcohol-does-not-protect-against-covid-19-and-its-access-should-be-restricted-during-lock-down.html> (last visited Nov. 11, 2024).

compared to the previous year.<sup>35</sup> While we do not yet have a clear picture of how drinking behaviors have evolved among different populations since the winding down of COVID-19-related restrictions, researchers do know that alcohol-related deaths have accelerated since the pandemic.<sup>36</sup> Between 2018 and 2019, 145,253 Americans died from excessive alcohol use, whereas between 2020 and 2021, 178,307 died.<sup>37</sup> There is little to no research on the impacts the change in American drinking will have on the rates of preventable cancers, as this may not surface for years to come.

## II. WHO'S RESPONSIBLE?

### *A. Big Alcohol Producers Deploy Strategies and Tactics to Prevent Regulation, Consumer Safety, and Public Awareness*

For decades, the alcohol industry has engaged in misinformation campaigns that undermine the public's understanding of the cancer risks associated with their products.<sup>38</sup> A qualitative study published in the *Drug and Alcohol Review Journal* analyzed studies, reports, websites, and other documents discussing cancer and alcohol sourced from twenty-six different alcohol industry-affiliated public relations organizations and alcohol producers.<sup>39</sup> Researchers found the groups' messaging could be broken down into three different strategies: (1) "denying, disputing or selectively omitting the relationship between alcohol consumption and cancer[;]" (2) "mentioning some risk of cancer, but obscuring, misrepresenting or obfuscating the nature or size of that risk[;]" and (3) "focusing discussion away from the independent effects of alcohol in increasing the risk of common cancers."<sup>40</sup>

Concerning the first strategy, five of the organizations analyzed outright denied that any relationship between alcohol and cancer exists, despite overwhelming evidence to the contrary.<sup>41</sup> The vast majority of websites analyzed (13 out of 21 public relations firms and 5 out of 5 alcohol producers) either fail to mention cancer as a health risk at all—despite featuring information about other

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<sup>35</sup> See Pollard, *supra* note 33; see also *About Nielsen*, THE NIELSEN CO. (2024), <https://www.nielsen.com/about-us/about/> (explaining that Nielsen is a "global leader in audience measurement, data and analytics, shaping the future of media").

<sup>36</sup> Marissa B. Esser, et al., *Deaths from Excessive Alcohol Use – United States, 2016-2021*, 73(8) *MORBIDITY & MORTALITY WKLY. REP.* 154, 156–57 (2024), <https://www.cdc.gov/mmwr/volumes/73/wr/pdfs/mm7308a1-H.pdf>.

<sup>37</sup> *Id.* at 156–57.

<sup>38</sup> Petticrew, *supra* note 11, at 294, 299–300.

<sup>39</sup> *Id.* at 293–94.

<sup>40</sup> *Id.* at 297–98.

<sup>41</sup> *Id.* at 297.

health risks—or they selectively omit mention of specific cancers.<sup>42</sup> The latter strategy is the most common approach for distorting the risk by acknowledging some risks but “obscuring, misrepresenting or obfuscating the nature or size of that risk.”<sup>43</sup> Nearly half of the organizations studied claim that cancer is only a risk for “heavy, excessive or binge drink[ing].”<sup>44</sup> Public relations firms often used additional tactics, such as refuting the link between alcohol use and cancer while claiming that moderate alcohol use has health benefits.<sup>45</sup> Finally, industry organizations commonly cite other “real and potential risk factors” including genetics, age, and socioeconomic factors as contributors to cancer as a way to minimize the role alcohol in causing cancer.<sup>46</sup> Interestingly, the organizations studied seemed particularly focused on misrepresenting the risks of breast and colorectal cancer associated with drinking.<sup>47</sup> While we do not know the reasoning behind this focus, one can surmise that the industry is trying to distance itself from two of the most common cancers Americans experience.<sup>48</sup>

Big Alcohol also spends heavily to impede public health efforts to raise awareness of cancer risks associated with alcohol use. In the United States, regulators have tried and failed to include cancer risk information on alcohol labels several times. Novelty, the passage of the Alcohol Beverage Labeling Act of 1988 required domestic sales to include a warning label for several health risks, such as driving while pregnant or driving.<sup>49</sup> Under that law, the Secretary of the Treasury, in consultation with the Surgeon General, must report to Congress any new scientific information that “would justify a change in [the labeling

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<sup>42</sup> *Id.* (“For example, Pernod’s ‘Wise Drinking’ brochure discusses the need to ‘combat unhealthy drinking habits’, and lists ‘mental retardation in children’ as among the most common consequences of alcohol consumption but presents no information on cancer. Diageo’s DrinkIQ.com website has a section entitled ‘Alcohol’s short-term and long-term effects on your body’ .... It does not mention cancer.”).

<sup>43</sup> *Id.*

<sup>44</sup> *Id.*

<sup>45</sup> *Id.* at 298 (“Claiming or implying that...the evidence of a causal relationship is not trustworthy...Despite the lack of evidence for the protective effects of alcohol consumption on cancer, a wide range of protective effects are claimed in industry websites.”).

<sup>46</sup> *Id.* at 298-99.

<sup>47</sup> *See id.* (listing several examples of industry claims that cast doubt on the causal relationship between alcohol consumption and breast cancer as well as claims that alcohol consumption may help prevent colorectal cancer).

<sup>48</sup> *See Common Cancer Types*, NAT’L CANCER INST., <https://www.cancer.gov/types/common-cancers#:~:text=The%20most%20common%20type%20of,are%20combined%20for%20the%20list> (listing breast and colorectal cancer as two most common in the United States) (May 10, 2024), <https://web.archive.org/web/20241005062017/https://www.cancer.gov/types/common-cancers>.

<sup>49</sup> *See* Alcohol Beverage Labeling Act, Pub. L. No. 100-690, Title VIII, § 204, 102. Stat. 4181, 4519 (1988) (giving the specific warning label required to be placed on all alcohol sales).

requirements].”<sup>50</sup> In the thirty-six years since passing the Act, Congress has never changed the language, despite overwhelming new scientific evidence demonstrating that various diseases stem from alcohol use.<sup>51</sup> Several national public health organizations recently submitted a petition asking for cancer to be added to the warning level. As of 2024, the Surgeon General and Secretary of the Treasury had yet to make any changes, even though the Surgeon General’s report in 2016 noted the link between alcohol and cancer.<sup>52</sup> While transparency into the behind-the-scenes decision-making is lacking, aggressive lobbying by alcohol producers has almost certainly had a substantial effect.

Abroad, regulators face similar pushback through lobbying and public relations campaigns. In Canada, public health officials launched a pilot program in the Yukon Territory where alcoholic beverages featuring a cancer warning label were sold in the only government-run liquor store in the region.<sup>53</sup> However, the alcohol industry mobilized quickly to prevent any impact on sales. Within a month of its launch, the program was successfully halted due to interference from the alcohol industry, including a media blitz and lobbying.<sup>54</sup> Roughly a year later, the Canadian government provided public health officials with permission to continue the program, under the condition that all references to alcohol and cancer be removed.<sup>55</sup> In other words, the government caved to alcohol industry

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<sup>50</sup> *Id.* § 206.

<sup>51</sup> Alcohol Justice, et al., Petition for a Report to Congress Supporting a Label on Alcoholic Beverages Warning the Public that Consumption Can Cause Cancer, Including Breast and Colon Cancer, 2-3 (Oct. 21, 2020), <http://alcoholjustice.org/images/downloadables/Citizen-petition-re-alcohol-cancer-warning.pdf>, <https://web.archive.org/web/20230916072947/http://alcoholjustice.org/images/downloadables/Citizen-petition-re-alcohol-cancer-warning.pdf>.

<sup>52</sup> *Facing Addiction in America: The Surgeon General’s Report on Alcohol, Drugs, and Health*, OFF. THE SURGEON GEN., U.S. DEP’T HEALTH & HUMAN SERVS., 1-12 (2016), [https://www.ncbi.nlm.nih.gov/books/NBK424857/pdf/Bookshelf\\_NBK424857.pdf](https://www.ncbi.nlm.nih.gov/books/NBK424857/pdf/Bookshelf_NBK424857.pdf) (“Alcohol misuse is associated with liver and pancreatic diseases, hypertension, reproductive system disorders, trauma, stroke, FASD, and cancers of the oral cavity, esophagus, larynx, pharynx, liver, colon, and rectum. For breast cancer, studies have shown that even moderate drinking may increase the risk.”).

<sup>53</sup> Kate Vallance, et al., News Media and the Influence of the Alcohol Industry: An Analysis of Media Coverage of Alcohol Warning Labels with a Cancer Message in Canada and Ireland, *J. STUD. ON ALCOHOL & DRUGS* 273, 275 (Mar. 2020).

<sup>54</sup> *Id.* at 274 (stating that alcohol industries in the Northwest Territories objected to additional messaging stating that alcohol can cause cancer, despite already using warning labels referencing impaired driving and general health risks).

<sup>55</sup> *Id.* at 275.



pressure.<sup>56</sup>

Similarly, the alcohol industry fought hard to remove cancer warning label requirements from an alcohol regulation bill in Ireland in 2018.<sup>57</sup> After years of work by members of the Irish Parliament and public health advocates, the bill nearly died in the upper house of Parliament, largely due to the opposition from the alcohol industry to the proposed cancer warning labels, despite having broad support overall.<sup>58</sup> The bill contained provisions that would regulate the alcohol industry in a variety of ways, including establishing “minimum pricing [for alcoholic beverages], structural separation of alcohol from other products in stores; bans on alcohol sponsorship, [and] restrictions on marketing and advertising;” however, the industry focused heavily on defeating the cancer warning label specifically.<sup>59</sup> Ultimately, regulators prevailed, and Ireland became the first nation in the world to require a cancer warning label on alcoholic beverages.<sup>60</sup>

Nevertheless, the intense uptick in messaging and lobbying that the alcohol industry deployed against cancer warnings specifically, is telling. Similar fights have broken out in Vietnam, Africa, and South Korea, where industry lobbying successfully watered down the cancer messaging now required on alcoholic beverages sold in South Korea.<sup>61</sup>

### *B. Secret Tobacco and Alcohol Industry Alliances have Organized Against Regulation for Decades*

One of the most surprising discoveries from the trove of Master Settlement documents was the alliance that formed between Big Alcohol and Big Tobacco in the 1980s as part of the effort to stop tobacco regulation and taxes.<sup>62</sup>

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<sup>56</sup> *Id.* (“The territorial government agreed to resume the study in February 2018 on the condition that the cancer warning label be permanently removed from rotation to avoid potential litigation by the alcohol industry”).

<sup>57</sup> *Id.*

<sup>58</sup> *Id.*

<sup>59</sup> *Id.* at 275, 278-80.

<sup>60</sup> Clare Slattery, *How Ireland beat the odds to introduce cancer warning labels on alcohol*, WORLD CANCER RSCH. FUND INT’L, (Feb. 5, 2024), <https://www.wcrf.org/how-ireland-beat-the-odds-to-introduce-cancer-warning-labels-on-alcohol/#:~:text=From%202026%2C%20all%20alcohol%20products,of%20alcohol%20consumption%20to%20cancer.> (“From 2026, all alcohol products sold in the Republic of Ireland will be required to state: ‘There is a direct link between alcohol and fatal cancers.’”).

<sup>61</sup> Thomas F. Babo, *The Arrogance of Power: Alcohol Industry Interference With Warning Label Research*, 81(2) J. STUD. ON ALCOHOL & DRUGS 222, 223 (2020), <https://www.jsad.com/doi/full/10.15288/jsad.2020.81.222>.

<sup>62</sup> See Jiang & Ling, *supra* note 10, at 852 (exploring collaboration

While this alliance does not seem to make much sense at first glance, further examination shows striking similarities between the two industries. Both industries are heavily regulated, and both products are known to be highly addictive.<sup>63</sup> Both industries routinely use marketing strategies to target minority populations and children.<sup>64</sup> Moreover, many of the alcohol industry's arguments against cancer warning labels mirror the messaging of Big Tobacco facing regulation in the 1980s and 1990s.<sup>65</sup>

Their shared interests do not end with policy agendas and marketing strategies—many of the largest tobacco companies own or previously owned sizable interests in some of the largest alcohol producers. From 1982 to 1987, cigarette maker RJ Reynolds owned the Heublin Spirits and Wine Company.<sup>66</sup> Phillip Morris, the tobacco giant behind popular cigarette brands like Marlboro, owned the Miller Brewing Company from 1969 to 2002.<sup>67</sup> Until its acquisition by Anheuser-Busch InBev in 2016, one of the two largest shareholders of SABMiller (producer of Miller Coors beverages) was tobacco conglomerate Altria Group.<sup>68</sup> As of July 2023, Altria Group still maintained a 10% interest in Anheuser-Busch

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between the tobacco and alcohol industries to shape public health policies).

<sup>63</sup> *Id.* at 852-53.

<sup>64</sup> See David J. Moore, et al., *Target Marketing of Tobacco and Alcohol-Related Products to Ethnic Minority Groups in the United States*, 6 ETHNICITY & DISEASE 83, 90 (1996), <https://www.jstor.org/stable/45409638> (“The data indicate that there is a significantly higher level of spending in terms of [alcohol marketing] billboard dollars per square mile for the cities with higher representations of minorities”); Alisa A. Padon, et al., *Alcohol brand use of youth-appealing advertising and consumption by youth and adults*, 7(1) J. PUB. HEALTH RSCH. 22, 27 (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5941256/> (“We found that alcohol brands using more youth appealing content were more likely to be consumed by youth than adults.”); Jennifer L. Brown, et al., *Spinning a global web: tactics used by Big Tobacco to attract children at tobacco points-of-sale*, 32 TOBACCO CONTROL 645, 648 (2023), <https://tobaccocontrol.bmj.com/content/32/5/645> (“Our findings indicate that the major multinational tobacco companies—namely BAT, Imperial, JTI and PMI—use similar marketing tactics at [points-of-sale] globally to attract children and youth to cigarettes.”).

<sup>65</sup> See Jiang & Ling, *supra* note 10, at 852, 856 (noting regulators’ designation of certain tactics as “prohibitionist”); Andrei Sirabonian, *Why Tobacco Litigation Has Not Been Successful in the United Kingdom: A Comparative Analysis of Tobacco Litigation in the United States and the United Kingdom*, 25 NW. J. INT’L L. & BUS. 485, 487 (2005) (stating that tobacco companies argued, in part, that they should not be held responsible for the misuse of their products when it was widely known that those products could be hazardous to your health).

<sup>66</sup> Jiang & Ling, *supra* note 10, at 852.

<sup>67</sup> *Id.*

<sup>68</sup> Martinne Geller & Phillip Blenkinsop, *SABMiller investors cheer \$100 billion-plus AB InBev takeover*, REUTERS (Sept. 28, 2016, 6:22 AM), <https://www.reuters.com/article/idUSKCN11Y0QY/#:~:text=SAB%20backed%20the%20higher%20offer,did%20not%20vote%20on%20Wednesday> (covering the large-scale acquisition’s impact on the industry).

InBev.<sup>69</sup>

A 2014 systematic analysis of Master Settlement documents also revealed that the tobacco and alcohol industries cooperated to thwart public health regulation by focusing on tobacco taxes, clean indoor air laws, and advertising and marketing restrictions.<sup>70</sup> As public opinion on the health impacts of tobacco began to shift in the 1980s, a slew of bills at the state and federal levels were proposed to raise taxes on cigarettes.<sup>71</sup> In response to these efforts, the tobacco industry formed the Consumer Tax Alliance (CTA), a national coalition aimed to fight tax increases on tobacco products.<sup>72</sup> Four of the seven corporations funding the Alliance were alcoholic beverage companies, (Seagrams, Miller Beer, Guinness, and Sazerac) contributing six hundred thousand dollars to the organization’s efforts, while Big Tobacco companies contributed roughly four million dollars.<sup>73</sup> As part of their strategy to stop tobacco excise taxes, the coalition aired ads focused instead on gas and beer excise tax increases, building public opposition to excise taxes as a whole, which was then used to reduce the amount of tobacco excise taxes to half of what was originally proposed.<sup>74</sup>

The alcohol industry also supported the tobacco industry’s astroturfing<sup>75</sup> efforts to stop clean indoor air laws.<sup>76</sup> In 1986, RJ Reynolds Tobacco Company founded an advocacy organization called The Partisan Project, which distributed the *Regulatory Watch*—a newsletter designed to inform consumers about proposed clean air legislation in their state and offer guidance on opposing the legislation.<sup>77</sup> The Partisan Project described itself as the “public voice comprised of individuals nationwide speaking out on an ongoing basis and their own volition in opposition to biased and emotional rhetoric and unfair discriminatory harassment of smokers.”<sup>78</sup> In 1987, the executive director of the National Liquor

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<sup>69</sup> Wealth Insights, *It’s Time That Altria Unleashes Its \$11 Billion Ace in the Hole*, SEEKING ALPHA (Jul. 20, 2023, 6:00 AM), <https://seekingalpha.com/article/4618320-its-time-altria-unleashes-11-billion-anheuser-busch-stake> (analyzing Altria’s stake in Anheuser-Busch InBev).

<sup>70</sup> Jiang & Ling, *supra* note 10, at 853.

<sup>71</sup> *Id.*

<sup>72</sup> *Id.*

<sup>73</sup> *Id.* at 855.

<sup>74</sup> *Id.*

<sup>75</sup> See *Astroturfing*, MERRIAM-WEBSTER, <https://www.merriam-webster.com/dictionary/astroturfing> (last visited Oct. 29, 2024) (defining astroturfing as “organized activity that is intended to create a false impression of a widespread, spontaneously arising, grassroots movement in support of or in opposition to something (such as a political policy) but that is in reality initiated and controlled by a concealed group or organization (such as a corporation”).

<sup>76</sup> See Jiang & Ling, *supra* note 10, at 855.

<sup>77</sup> See *id.*

<sup>78</sup> *Id.*

Store Association (NLSA) gave the Partisan Project its list of 25,000 members, as well as speaking engagements at three of its national conventions.<sup>79</sup> In those presentations, RJ Reynolds stressed the high correlation between liquor store customers and smokers, stating that “close to half of all people who are high volume buyers of distilled spirits are smokers. . . today tobacco is the focus of prohibitionists. Alcohol follows close behind.”<sup>80</sup> By 1989, the executive leadership of NLSA and the National Licensed Beverage Association were fully committed to The Partisan Project’s agenda.<sup>81</sup>

Finally, Big Tobacco and Big Alcohol cooperated to defeat advertising and marketing restrictions. The Tobacco Institute, the “principal tobacco industry trade association,” along with the Distilled Spirits Council of United States (DISCUS) and the Beer Institute, funded First Amendment-based challenges to both tobacco and alcohol marketing restrictions from the 1970s to at least the 1990s, framing the issue as an attack on advertising rights.<sup>82</sup>

*C. Litigation Against Corporate Bad Actors can Lead to Changes in Public Opinion and Regulation*

Public health-driven product liability litigation has resulted in positive impacts for consumers in a variety of contexts. In addition to compensating victims for their injuries, product liability litigation efforts have increased consumer safety features on products such as automobiles, removed hazardous products such as asbestos from the market, and deterred future manufacturers from negligent behavior in various industries.<sup>83</sup>

One of the most impactful public health litigation efforts has been state actions against Big Tobacco companies and the subsequent Master Settlement.<sup>84</sup> As a result of millions of internal documents that exposed the tobacco industry’s unethical practices, including misinformation campaigns, marketing targeting adolescents, and aggressive lobbying, public opinion of the tobacco industry has shifted dramatically and political support for tobacco regulation has grown.<sup>85</sup>

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<sup>79</sup> *Id.* at 856.

<sup>80</sup> *Id.*

<sup>81</sup> *Id.*

<sup>82</sup> *Id.* at 852, 856 (stating that the free speech argument was considered the most effective).

<sup>83</sup> James Mosher, *Litigation and alcohol policy: lessons from the US Tobacco Wars*, 104 ADDICTION 27, 27 (2009), <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1360-0443.2008.02432.x>.

<sup>84</sup> *Id.*

<sup>85</sup> *Id.* at 28-29; see Frank A. Sloan & Justin G. Trogon, *The Impact of the Master Settlement Agreement in Cigarette Consumption*, 23(4) J. POL’Y ANALYSIS & MGMT. 843, 843-44 (2004), [https://onlinelibrary.wiley.com/doi/abs/10.1002/pam.20050?casa\\_token=1nSdQ5biowUAAAAA:t](https://onlinelibrary.wiley.com/doi/abs/10.1002/pam.20050?casa_token=1nSdQ5biowUAAAAA:t)

Excise taxes imposed on cigarettes have increased significantly in most states since the Master Settlement in 1998, with some states increasing their excise taxes on cigarettes several times.<sup>86</sup> Between 2000 and 2010, New York State increased cigarette excise taxes four times, with a cigarette tax now totaling \$5.35 per pack.<sup>87</sup> Similarly, the District of Columbia raised cigarette taxes three times between 2003 and 2018 and now has a cigarette tax of \$4.50 per pack.<sup>88</sup> While the frequency of excise tax increases on cigarettes has remained relatively steady since 1980, the average tax increase amount per pack has roughly tripled from 1998 to 2023.<sup>89</sup> It is clear that lawmakers at the state level have become increasingly comfortable going after the tobacco industry, and these excise taxes have proven to be one of the most effective methods for reducing smoking rates among high-risk populations including youth, young adults, and people with lower socio-economic status.<sup>90</sup>

More recently, high-profile litigation against opioid manufacturers and pharmacies, which was largely modeled after tobacco litigation strategies, has achieved similar beneficial outcomes, including “compensation for abating opioid harms, deterrence of corporate malfeasance by holding many companies accountable for their behavior and requiring them to change it, and acute public awareness of the risks of opioid addiction.”<sup>91</sup> While regulation in this instance came first—in the form of greater restrictions on prescribing—there is no doubt that the massive liability faced by opioid manufacturers and pharmacies will

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Walter J. Jones & Gerard A. Silvestri, *The Master Settlement Agreement and Its Impact on Tobacco Use 10 Years Later: Lessons for Physicians About Health Policy Making*, 137(3) CHEST 692, 692 (2010), <https://www.sciencedirect.com/science/article/abs/pii/S0012369210601481>.

<sup>86</sup> Ann Boonn, *Cigarette Tax Increases by State per Year 2000-2024*, Campaign for Tobacco-Free Kids (June 4, 2024), <https://www.tobaccofreekids.org/us-resources/fact-sheet/cigarette-tax-increases-by-state-per-year-2000-2017>.

<sup>87</sup> Jennifer Solomon, *New York State’s \$1 Cigarette Tax Hike Goes into Effect September 1st*, AM. LUNG ASS’N (Aug. 31, 2023), <https://www.lung.org/media/press-releases/nys-cigarette-tax2023#:~:text=Beginning%20Sept.,per%20pack%20of%2020%20cigarettes>.

<sup>88</sup> Boonn, *supra* note 86.

<sup>89</sup> *Id.* (demonstrating that in the ten years following the Master Settlement, states passed 105 unique cigarette tax increases; comparatively, in the ten years preceding the Master Settlement, states passed 81 tax increases).

<sup>90</sup> Pearl Bader, et al., *Effects of Tobacco Taxation and Pricing on Smoking Behavior in High-Risk Populations: A Knowledge Synthesis*, 8(11) INT’L J. ENV’T RSCH. & PUB. HEALTH 4118, 4119 (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3228562/>.

<sup>91</sup> Rebecca L. Haffajee, *The Public Health Value of Opioid Litigation*, 48(2) J. L. MED. & ETHICS 279, 280 (2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7481928/#:~:text=Opioid%20litigation%20also%20has%20achieved,the%20risks%20of%20opioid%20addiction>.

impact that industry’s internal business practices for decades to come.<sup>92</sup> Opioid litigation is also similar to tobacco litigation in that litigation has resulted in a national opioid settlement where numerous large corporate defendants have agreed to contribute to funds that states are then supposed to use for public health-related efforts.<sup>93</sup> Both the 2021 and 2022 opioid settlements require that participating states use at least 85% of the funds to invest in opioid epidemic abatement efforts.<sup>94</sup>

While these examples are not perfectly analogous, they demonstrate that public health product liability litigation can drive public opinion and break industry lobbyist strongholds in federal and state governments. The resulting regulation, while also not perfect, can positively affect public health.

### III. LESSONS FROM PAST LITIGATION

#### *A. The Tobacco Wars Paved the Way for Successful Public Health Litigation*

The first legal theories proposing to take on tobacco companies for smokers’ health issues arose in the 1950s.<sup>95</sup> In 1954, the first individual plaintiff brought a case against a tobacco company in *Pritchard v. Liggett & Myers Tobacco Co.*<sup>96</sup> While many legal experts believed that plaintiffs would eventually prevail by overwhelming the tobacco industry with a flood of individual lawsuits, *Pritchard v. Liggett* and the subsequent 300-plus lawsuits against tobacco companies failed.<sup>97</sup> The tobacco industry simply outspent and outmuscled their opposition.<sup>98</sup> Moreover, most cases asserted fraud, negligence, and/or breach of warranty, which the tobacco companies were able to easily defeat by arguing that illnesses engendering this litigation were unforeseeable results of smoking cigarettes.<sup>99</sup> By the mid-1960s, theories of strict product liability against tobacco companies began to gain favor, due to the publishing of the Restatement (Second) of Torts, which provided that companies that sell any “product in a defective

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<sup>92</sup> *Executive Summary of National Opioid Settlement*, NAT’L OPIOIDS SETTLEMENT (Sept. 8, 2023), <https://nationalopioidsettlement.com/executive-summary/> [hereinafter OPIOID SETTLEMENT]. In addition to the \$26 billion settlement with Johnson & Johnson, McKesson, Cardinal Health, and AmerisourceBergen, Teva has agreed to pay up to \$3.34 billion, CVS will pay \$4.9 billion and Walgreens will pay \$5.52 billion just to name a few.

<sup>93</sup> *Id.*

<sup>94</sup> *Id.*

<sup>95</sup> Sirabionian, *supra* note 65, at 486.

<sup>96</sup> *Id.*

<sup>97</sup> *Id.*

<sup>98</sup> *Id.* at 486-87.

<sup>99</sup> *Id.*

condition unreasonably dangerous to the user” could face strict liability regardless of whether that company breached a duty.<sup>100</sup>

In 1965, Congress passed the Federal Cigarette Labeling and Advertising Act which required cigarette companies to include labels on their packaging stating “Caution: Cigarette Smoking May Be Hazardous to Your Health.”<sup>101</sup> However, much to the dismay of public health advocates, the new warning labels became a shield of immunity that cigarette companies could hide behind, taking the position that smokers were now aware of and assumed the risks associated with smoking.<sup>102</sup> This position was successful until 1996, when the first individual plaintiff prevailed against a tobacco company, securing a \$750,000 judgment for damages stemming from both negligence and strict liability claims.<sup>103</sup> In *Carter v. Brown and Williamson*, Grady Carter—a smoker for forty-four years—and his wife sued the manufacturer of Lucky Strike cigarettes after he was diagnosed with lung cancer.<sup>104</sup> Ultimately, the jury found the cigarette company liable for his injuries, marking the first time a tobacco company was found liable for smoking-related health harms.<sup>105</sup>

### *B. States Attorneys General Step In*

That same year, attorneys general in Mississippi, Florida, West Virginia, Massachusetts, and Louisiana joined forces, sued Liggett and Meyers Tobacco Company, and secured the first settlement against the cigarette company.<sup>106</sup> As a result, regulators finally had access to Big Tobacco’s internal corporate documents.<sup>107</sup> Panic among the remaining Big Tobacco corporations ensued and, by the following year, a national settlement was reached with what seemed only two years earlier to be an unbeatable industry.<sup>108</sup>

In large part, these actions, along with several state actions that followed, were successful because attorneys general brought claims under a theory of

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<sup>100</sup> Restatement (Second) of Torts § 402A (Am. L. Inst. 1965).

<sup>101</sup> Sirabionian, *supra* note 65, at 487-88.

<sup>102</sup> *Id.* at 489.

<sup>103</sup> *Id.* at 491; *Carter v. Brown and Williamson Tobacco Corp.*, No. 95-934-CA CV-B (Fla. Duval Cir. Ct. Dec. 5, 1996) (noting that the award was ultimately overturned by the Florida District Court of Appeals on statute of limitation grounds, however momentum against the tobacco industry had already gained traction).

<sup>104</sup> *Carter v. Brown and Williamson Tobacco Corp.*, 778 So. 2d 932, 934-935 (Fla. 2000).

<sup>105</sup> *Id.* at 935; Sirabionian, *supra* note 65, at 491.

<sup>106</sup> Richard P. Ieyoub & Theodore Eisenberg, *State Attorney General Actions, the Tobacco Litigation, and the Doctrine of Parens Patriae*, 74 TUL. L. REV. 1859, 1861 (2000).

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*

parens patriae, allowing a state to “recover costs or damages incurred because of behavior that threatens the health, safety, and welfare of the state’s citizenry.”<sup>109</sup> This quasi-sovereign interest of states protecting the well-being of its citizens is what formed the basis for the parens patriae tobacco litigation.<sup>110</sup> States were able to argue they had a duty to protect their citizens from the health hazards the tobacco industry posed to those citizens, in part because the public did not effectively understand the harm.<sup>111</sup>

### *C. States Used the Parens Patriae Playbook from Tobacco Litigation to Go After Opioid Manufacturers and Distributors*

Like tobacco litigation of the 1990s, individual opioid tort claims have largely been “replaced by aggregate litigation” in multidistrict litigation (MDL) forums spearheaded by states’ attorneys general.<sup>112</sup> States have invoked the doctrine of parens patriae to sue opioid manufacturers like Purdue Pharma and Johnson & Johnson for injuries sustained by citizens; the states themselves have also invoked the doctrine to redress claims for their healthcare and emergency services costs.<sup>113</sup> Settlements and bankruptcy proceedings have already occurred in cases with a number of large defendants, including Johnson & Johnson, McKesson, Cardinal Health, and AmerisourceBergen, totaling over \$26 billion.<sup>114</sup> As with tobacco litigation, it would seem that these initial settlements have broken the dam and more settlements will likely follow.

### *D. Product Liability Actions from Alcohol-Caused Cancer Injuries May Prove Viable*

Similar to tobacco companies of the 1960s and 1970s, alcohol producers have effectively hidden behind the assumption of risk defense when faced with actions for harms related to alcoholism, binge drinking, and other predictable injuries.<sup>115</sup> Courts have consistently viewed such risks as widely known to the

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<sup>109</sup> *Id.* at 1862-63.

<sup>110</sup> See *Alfred L. Snapp & Son, Inc. v. Puerto Rico*, 458 U.S. 592, 593–94, 601 (1982) (holding that valid parens patriae standing requires a state to assert an interest related to its sovereignty, including enforcing its civil and criminal laws, and recognizing quasi-sovereign interests such as the general physical and economic well-being of its residents, which later underpinned states’ actions against tobacco companies).

<sup>111</sup> Ieyoub, *supra* note 106, at 1863.

<sup>112</sup> Rebecca L. Haffajee, et al., *Government Opioid Litigation: The Extent of Liability*, 70 DEPAUL L. REV., 275, 278 (2020).

<sup>113</sup> *Id.* at 279.

<sup>114</sup> *Id.* at 280; OPIOID SETTLEMENT, *supra* note 92.

<sup>115</sup> Campbell, *supra* note 5, at 174; *Garrison v. Heublein, Inc.*, 673 F.2d 189 (7th Cir. 1982).



public, meaning that producers have not had a duty to warn the public of the risks.<sup>116</sup> However, as explored above, there is a strong argument that the health risks that arise from alcohol-caused cancer are not widely known. Further, the alcohol industry has expended enormous amounts of money and manpower to keep the alcohol-cancer connection out of the public's attention. The abundance of public health research on the alcohol-cancer connection supports the likelihood that an individual plaintiff could show that his or her cancer-related injuries were caused by alcohol consumption. Therefore, it is possible that, under a theory of strict product liability, an individual plaintiff may prevail where others have failed with addiction or binge drinking actions because (1) the alcohol industry is aware of their products' cancer risks, (2) they have taken steps to suppress public knowledge of those risks, and (3) the public is not widely aware of that risk.

The most noteworthy limitations of the individual product liability approach are the same limitations experienced by individual plaintiffs in tobacco and opioid litigation. First, there is a large disparity in resources between parties, making it easier for alcohol producers to “run out the clock” and force plaintiffs to withdraw their claims when they can no longer afford litigation costs. Second, just like with opioid litigation, alcohol producers will point to potential misuse of their products as the cause of cancer. While evidence would suggest otherwise, the alcohol industry is likely to take an approach that their products, when used in moderation, do not pose a risk for cancer. Third, jurisprudence until now has favored producers, as courts in other alcohol-related injuries have consistently found risks associated with alcohol consumption to be widely known and not actionable. This has narrowed the odds of a victory when plaintiffs have little to no authority supporting their position.

#### *E. Parens Patriae Actions Present Both Benefits and Limitations*

As we have seen in tobacco and opioids, a parens patriae litigation strategy can succeed where individual lawsuits may not. One of the most significant benefits from a parens patriae action is the collective power that states bring against a large defendant like RJ Reynolds, Johnson & Johnson, or Anheuser-Busch InBev. For the first time, the tobacco companies and opioid manufacturers were matched in resources and legal support. While other collective actions like class actions also pool resources, “[c]ourts have been extremely reluctant to certify classes for mass tort claims regarding tobacco litigation,” mainly because of the individualized nature of tobacco-related injuries.<sup>117</sup> More recently, a class action of 500,000 Florida residents against RJ

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<sup>116</sup> Campbell, *supra* note 5, at 174.

<sup>117</sup> Sirabonian, *supra* note 65, at 494.

Reynolds resulted in an award of \$144.8 billion, the largest award for plaintiffs to date in a tobacco case.<sup>118</sup> Ultimately, however, Florida’s Third District Court of Appeals overturned that award and ordered the class decertified based on the diversity of injuries.<sup>119</sup> A class of alcohol-caused cancer victims would likely face the same certification challenges because of the individualized nature of their injuries.

Because a state can invoke its quasi-sovereign interest in protecting the general health and welfare of its citizens under a theory of *parens patriae*, it is not held to the same—often unachievable—standards as certified classes or individual plaintiffs. Similar to product liability, states can frame the alcohol-cancer connection as an especially high risk to public welfare because the alcohol industry has been so effective in suppressing public understanding of it. Finally, successful actions in the tobacco and opioid context provide strong precedential support for a *parens patriae* action against alcohol manufacturers.

State *parens patriae* actions, however, present some major limitations. From a legal perspective, a state must demonstrate that the interest it is attempting to protect is beyond the interests of the individual private parties it represents, and, to date, the U.S. Supreme Court has not yet defined exactly what criteria the state interest in public welfare can and cannot be.<sup>120</sup> Though largely viewed as a success for plaintiffs, tobacco and opioid settlements have prevented courts from defining the broad and undefined nature of what interests support *parens patriae* actions.

There are also serious political limitations of states suing alcohol producers—at least for now. Many seemingly natural state allies in other respects may not be quick to join actions against alcohol producers due to local political support for the industry. Many state and local governments rely heavily on alcohol tax revenue and boutique breweries, wineries, and distilleries are often seen as an economic boon for small cities as they draw tourism and support local economies.<sup>121</sup> While states can and should distinguish between large-scale alcohol manufacturers, like Anheuser-Busch InBev, and their local breweries, trade associations often enlist the help of local businesses to increase political pressure

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<sup>118</sup> *Id.* at 496.

<sup>119</sup> *Id.* at 496-97.

<sup>120</sup> Ieyoub, *supra* note 106, at 1882.

<sup>121</sup> See Tom Wark, *Politics Under the Influence: Examining Political Campaign Contributions and Lobbying Expenditures in the American Alcohol Industry 2017-2020*, WARK COMMS. (Feb. 22, 2021), <https://fermentationwineblog.com/wp-content/uploads/UnderTheInfluence.pdf> (stating alcohol has been a major source of revenue for state governments).

in other fights like tax increases.<sup>122</sup> Finally, alcohol producers spend extraordinary amounts of money in state legislatures to gain influence.<sup>123</sup> This political pressure will likely make some elected state attorneys general reluctant to pursue litigation. Nevertheless, public education about the risks of alcohol-related cancer may move some elected leaders to action.

#### *F. The Tide is Already Beginning to Turn*

Much like the late 1960s and early 1970s in the fight against tobacco, the public and some public health-minded policymakers are beginning to push back against an alcohol industry that has—until now—enjoyed near-total support. One only needs to scan social media to see that popular opinion regarding alcohol is already beginning to shift. Pop culture phenomena like “Dry January” and “California Sober” have become mainstream concepts and people are choosing to drink less alcohol.<sup>124</sup> Zero-proof liquor companies and dry bars have popped up across the United States.<sup>125</sup>

At the policy level, there are grassroots advocacy organizations in several states. At the national level, such organizations are advocating for a public-health-centered approach to alcohol policy.<sup>126</sup> As these movements continue to gain power through the passing of successful state and federal-level legislation—including but not limited to excise tax increases and marketing restrictions—public opinion will likely follow. In Oregon, the state’s preeminent health agency,

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<sup>122</sup> In the 2020 Oregon legislative session, I led a coalition of public health organizations to increase beer and wine taxes aimed at large producers. Opposition to that and other alcohol regulatory bills quickly materialized in the form of testimony from small businesses aligned with the Oregon Beer and Wine Distributors Association, a group funded by large-scale out-of-state producers, including Anheuser-Busch InBev.

<sup>123</sup> Client Profile: Anheuser-Busch InBev, OPEN SECRETS (last visited Oct. 30, 2024), <https://www.opensecrets.org/federal-lobbying/clients/summary?id=D000042510&cycle=2022>; see Tom Wark, *Politics Under the Influence: Examining Political Campaign Contributions and Lobbying Expenditures in the American Alcohol Industry 2017-2020*, WARK COMM. (Feb. 22, 2021), <https://fermentationwineblog.com/wp-content/uploads/UnderTheInfluence.pdf> (stating alcohol has been a major source of revenue for state governments).

<sup>124</sup> Carly Mallenbaum & Alice Feng, *Dry January has become Dry February and beyond*, AXIOS (Feb. 24, 2024), <https://www.axios.com/2024/02/24/dry-january-february-athletic-beer> (regarding the term “Dry January”); Ernesto Londoño, *What Does Being Sober Mean Today? For many, Not Full Abstinence*, N.Y. TIMES (Feb. 4, 2024), <https://www.nytimes.com/2024/02/04/us/addiction-california-sober.html> (regarding the term “California Sober”).

<sup>125</sup> Jonathan Chang & Meghna Chakrabarti, *Zero-proof: Behind the growing popularity of an alcohol-free lifestyle*, WBUR (Jan. 12, 2024), <https://www.wbur.org/onpoint/2024/01/12/zero-proof-life-behind-the-growing-popularity-of-an-alcohol-free-lifestyle>.

<sup>126</sup> See, e.g., OREGON RECOVERS, [www.oregonrecovers.org](http://www.oregonrecovers.org) (last visited Oct. 30, 2024); RECOVER ALASKA, <https://recoveralaska.org> (last visited Oct. 30, 2024); U.S. ALCOHOL POL’Y ALL., [www.alcoholpolicy.org](http://www.alcoholpolicy.org) (last visited Oct. 30, 2024).

Oregon Health Authority, launched a statewide public education campaign aimed at informing citizens of the risks of alcohol use and encouraging less frequent alcohol consumption.<sup>127</sup> In recent years, both Maryland and Anchorage, Alaska passed alcohol tax increases to reduce alcohol consumption rates among high-risk populations.<sup>128</sup> The next step in holding Big Alcohol accountable, however, must involve litigation.

*G. Individual Product Liability Cases will Erode Political Support for—and Highlight the Misdeeds of—Big Alcohol*

The time is now for individuals with alcohol-related cancer to bring claims against large alcohol producers. While actions may fail at first, just like the tobacco fight, these cases will shine a much-needed light on Big Alcohol's business practices and the health risks associated with their products. This approach will eventually turn popular and political opinion in favor of more regulation. If the tobacco fight is any indication, these cases can—at some point—provide enough political cover for select states' attorneys general to explore *parens patriae* actions. As seen with tobacco and opioids, the involvement of states will swiftly bring Big Alcohol to the settlement table. It took just one successful individual lawsuit against a tobacco company to turn the tide in the plaintiffs' favor, eventually triggering multiple state actions and forcing a national tobacco settlement.<sup>129</sup>

## CONCLUSION

Cancers resulting from alcohol use pose a significant risk to the health and welfare of Americans, in large part because the public is generally unaware of the alcohol-cancer connection. Efforts by the alcohol industry that largely mirror those by the tobacco companies of the 1980s to prevent the public from making

<sup>127</sup> RETHINK THE DRINK, AN INITIATIVE OF THE OREGON HEALTH AUTHORITY PUBLIC HEALTH DIVISION, <https://www.rethinkthedrink.com>, (last visited Oct. 30, 2024).

<sup>128</sup> Nicholas Sohr, *Alcohol tax hike passes Md. House Committee*, MD. HEALTHCARE FOR ALL (Apr. 9, 2011), <https://healthcareforall.com/alcohol-tax-hike-passes-md-house-committee/> (“That would be a great public health victory for Maryland.”); ANCHORAGE ASSEMBLY, ALCOHOL TAX FACT SHEET (March 2022), <https://www.muni.org/Departments/Assembly/PressReleases/Assembly%20Press%20Releases/2022-0307%20Alcohol%20Tax%20Information%20Sheet.pdf> (“[S]teady funding stream for programs to prevent and address the problems associated with substance misuse.”).

<sup>129</sup> See *Carter v. Brown and Williamson Tobacco Corp.*, 778 So. 2d 932, 934-935 (Fla. 2000). (holding that the district court erred and the Carters' claims were not barred); see Sirabonian, *supra* note 66, at 491 (explaining that as soon as the tobacco industry was defeated at the individual level, the momentum shifted rapidly in favor of plaintiffs and after this first victory, states' Attorney Generals joined forces to sue under *parens patriae*, which the tobacco industry could not outmuscle).

an informed decision about the use of their carcinogenic products further support this position. As a result, the alcohol industry is exposed to two new avenues of litigation against it: individual plaintiff product liability for cancer caused by alcohol use and parens patriae actions brought by states' attorneys general.

On balance, parens patriae actions are more likely to prevail due to access to greater resources and less restrictive jurisprudence, but we may be decades away from public opinion supporting such actions. However, like the trajectory of tobacco litigation, we must test the cancer product liability action in the courts first: A successful individual product liability lawsuit for cancer will likely break through the seemingly impervious shield of legal immunity the alcohol industry has enjoyed and tip the scales in favor of plaintiffs. Finally, successful or not, each lawsuit filed against the alcohol industry forces the industry to take positions against the alcohol-cancer connection that will compromise it in the future as the growing body of evidence becomes undeniable. Victory may not be today or tomorrow, but in each unsuccessful action, we lose forward toward justice.

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# WE SHOULDN'T FORGET: FINANCIAL AND ETHICAL BARRIERS TO ACCESSING LONG-TERM CARE FOR PATIENTS WITH ALZHEIMER'S DISEASE

*Taylor McGee Campbell\**

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## INTRODUCTION

Health care in the United States is overwhelmingly driven by financial motivations and incentives. Our healthcare system has become a business, a process which, over time, has dehumanized the entire concept of our system. Overworking staff, overcharging patients, restricting access, and allocating resources according to financial status all serve to ensure the “healthcare ATM” stays full and the system remains a booming industry. Doctors, hospitals, care facilities, and other providers deliver healthcare services, yet fail to provide adequate care for the health and well-being of individual patients. The healthcare system benefits from keeping people locked right outside the gates, healthy enough to build the economy and support the industry but just sick enough to remain reliant and willing to return. The goal of this article is not to say that all participants in the healthcare system are corrupt and performing unethically. I recognize that plenty of providers are committed to upholding the ethics of care that led them to enter the medical field. However, as this article will discuss, the healthcare system as a whole reflects a profound failure to adequately take care of patients, and we can no longer allow such injustice to be so widely tolerated and accepted.

### I. HYPOTHETICAL CASE STUDY

Margaret<sup>1</sup> is a 74-year-old female with a new diagnosis of middle-stage Alzheimer’s<sup>2</sup> disease. Margaret has three loving children who are adamant about finding the best possible care for her in a long-term memory care facility. Margaret’s husband died a few years ago and left her with virtually unlimited financial support to use for whatever she may need. Margaret’s daughter, Sarah, works remotely and is willing to relocate to be near the facility that Margaret is placed in so she can be involved in her day-to-day care. Because of her vast financial resources and an early diagnosis and room reservation, Margaret is admitted to a high-quality, privately funded live-in memory care unit where she can receive premium care twenty-four hours a day, seven days a week from a highly rated, individualized medical team. Margaret, although still slowly cognitively declining from Alzheimer’s, feels at home at the facility and is becoming established in the patient community—she has even started attending weekly group knitting classes. Margaret’s daughter, Sarah, has a wonderful

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<sup>1</sup> Margaret and all other individuals in the case study are completely fictional. However, all proposed scenarios are loosely based on common experiences of patients with Alzheimer’s disease and other types of dementia in long-term care facilities.

<sup>2</sup> What is Alzheimer’s Disease?, ALZHEIMER’S ASS’N, (last visited Oct. 31, 2024) <https://www.alz.org/alzheimers-dementia/what-is-alzheimers> (defining Alzheimer’s disease as the most common type of dementia, a brain disease that affects cognitive daily functioning).



relationship with the facility staff. The staff has grown especially fond of Margaret and goes out of their way to give Margaret special treatment.

Now, imagine Margaret has one son with minimal financial resources. Imagine he works as a dentist in a small town and has enough money to seek middle-quality care for his mother but he can only visit his mother after work and on the weekends because of his schedule. Margaret has insurance through Medicare<sup>3</sup> (the federally funded healthcare program for the elderly and disabled) and is placed in a skilled nursing care facility a few towns away until her son can figure out a more permanent plan.<sup>4</sup> Margaret shares a room with another patient and nurses check on her a few times a day. Margaret is comfortable but is frequently ignored by staff when she displays signs of confusion, difficulty completing tasks, social withdrawal, and other memory loss symptoms.<sup>5</sup> The staff at the facility only does the bare minimum to ensure Margaret is eating and taking her medications. Margaret's son is skeptical of the care provided by the staff but does not know enough to speak up nor does he have evidence of maltreatment to comfortably support his skepticism.

Finally, shift the facts and imagine Margaret has no living relatives, is on Medicaid<sup>6</sup> (the joint federal and state healthcare program for low-income individuals), and has very little savings or other financial resources.<sup>7</sup> Margaret was found wandering the streets of her small town in the middle of the night and was forced to move into the local nursing home. Margaret is now frequently abandoned in her room, confused about where she is, agitated by the “strangers” who surround her, and struggling to remember details that once defined her. Margaret becomes extremely malnourished and quickly deteriorates physically and cognitively until she is essentially mute and catatonic most of the time. The staff grows increasingly frustrated with Margaret's lack of cognitive ability and only visits her to deliver her meals and medication a few times each day. Other than these brief staff check-ins, Margaret remains in solitude most of the time and lives within her convoluted mind. Margaret dies approximately two years after

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<sup>3</sup> *Get Started with Medicare*, MEDICARE.GOV (last visited Oct. 30, 2024), <https://www.medicare.gov/basics/get-started-with-medicare>.

<sup>4</sup> *Skilled Nursing Facility (SNF) Care, Your Medicare Coverage*, MEDICARE.GOV (last visited Oct. 30, 2024), <https://www.medicare.gov/coverage/skilled-nursing-facility-snf-care>.

<sup>5</sup> *Alzheimer's Awareness*, GREEN SHOOT MEDIA (last visited Oct. 31, 2024), <https://greenshootmedia.com/images/September2020Sections/AlzheimersAwarenessPreview.pdf>.

<sup>6</sup> *Eligibility Policy*, MEDICAID.GOV (last visited Oct. 31, 2024), <https://www.medicaid.gov/medicaid/eligibility-policy/index.html>.

<sup>7</sup> *E.g., Am. Council on Aging, Medicaid Eligibility: 2024 Income, Asset, & Care Requirements for Nursing Homes & Long-Term Care*, MEDICAID PLANNING (Jan. 29, 2024), <https://www.medicaidplanningassistance.org/medicaid-eligibility/>.

being admitted to the facility.

### *A. Background*

These scenarios highlight the harsh realities of inadequacy of care in long-term care facilities. This article will analyze those realities within the context of a bioethical framework, as discussed by Beauchamp and Childress.<sup>8</sup> The four “principles” of biomedical ethics proposed by Beauchamp and Childress are autonomy, beneficence, nonmaleficence, and justice.<sup>9</sup> The above case study highlights the imbalance of moral principles, injustices in access to care, and the ultimate failure of our healthcare system to do what it is supposed to do—provide care. Further, this paper evaluates financing mechanisms in long-term care facilities (nursing homes, memory care units, etc.) for patients with Alzheimer’s disease, and other related dementias, through this ethical lens.

Virtue ethics rests on the foundation that a good person will do good things, and to be good, you must do good things.<sup>10</sup> We do good or “right” things because of automatic responses resulting from our good character.<sup>11</sup> Beauchamp and Childress identify five virtues applicable in our (nursing home staff) context: trustworthiness, integrity, discernment, compassion, and conscientiousness.<sup>12</sup> Aristotle suggested that humans are set apart because we can make choices based on reason.<sup>13</sup> To be a virtuous person, one must use reason to decide how to “be,” and how one will exercise virtues they believe to possess with rationality in order to make good choices.<sup>14</sup> The virtues chosen will become embedded in a person’s character and thus produce a desire to continue in virtuous behavior.<sup>15</sup>

Individuals in long-term care facilities are “embedded in care convoys” comprised of informal and formal caregivers, each with a duty, whether moral or legal, to provide care.<sup>16</sup> Due to this complex model of care, potential conflicts

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<sup>8</sup> Tom L. Beauchamp & James F. Childress, *Principles of Biomedical Ethics* (Oxford Univ. Press, 8th ed. 2019).

<sup>9</sup> *Id.* at 99, 155, 217, 267.

<sup>10</sup> *See* Beauchamp & Childress, *supra* note 8, at 411-12.

<sup>11</sup> *Id.* at 410.

<sup>12</sup> *Id.* at 32-36.

<sup>13</sup> Aristotle, *Nicomachean Ethics* bk. I, ch. 7, 1098a7–1098a8 (last visited Nov. 16, 2024), <https://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.01.0054%3Abook%3D1%3Achapter%3D7>.

<sup>14</sup> Beauchamp & Childress, *supra* note 8, at 409-15.

<sup>15</sup> *Id.*

<sup>16</sup> Candace Kemp, et al., *The Ethics in Long-Term Care Model: Everyday Ethics and the Unseen Moral Landscape of Assisted Living*, 41 *J. APPL GERONTOL.* 1143-52 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8967785/>.

arise at all levels—personal, professional, institutional and societal.<sup>17</sup> A convoy comprised of *virtuous* caregivers will be committed to doing things that serve their desires to achieve higher virtue. Likely, a system operating this way will be just, compassionate, and trustworthy, and will carry out the four principles of biomedical ethics by respecting autonomy, acting with beneficence, prioritizing nonmaleficence, and ensuring justice in treatment.<sup>18</sup> When conflicts arise, the team of virtuous caregivers strives to work in harmony to act virtuously to care for their patients. A system rooted in virtues is an ideal environment for patients, supporters, and staff in long-term care facilities.

## II. FRAMEWORK FOR FINANCING LONG-TERM CARE

### A. Overview

According to the Alzheimer’s Association, there are currently more than six million Americans living with Alzheimer’s disease and other related dementias.<sup>19</sup> Financial resources, among other things, greatly impact the quality of care patients with Alzheimer’s and other cognitive diseases have access to.<sup>20</sup> Memory care units typically cost \$1,000 or more per month than standard assisted living or nursing home care.<sup>21</sup>

According to the 2023 Genworth Cost of Care Survey, the average monthly cost of nursing home care for a semi-private room was \$8,669, and \$9,733 monthly for a private room.<sup>22</sup> Most memory care communities charge up-front fees that can range from \$1,000 all the way up to the cost of the first month’s rent.<sup>23</sup> Many communities offer special, intensive, personalized care for those who can afford a higher monthly rate.<sup>24</sup> The unique programs are tailored to encourage independence and higher quality of life for dementia patients, but not

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<sup>17</sup> See *id.*

<sup>18</sup> See Beauchamp & Childress, *supra* note 8.

<sup>19</sup> *Alzheimer’s Disease Facts and Figures*, ALZHEIMER’S ASS’N. (last visited Oct. 18, 2023), <https://www.alz.org/alzheimers-dementia/facts-figures>.

<sup>20</sup> See Nirali Desai, *Everything You Need to Know About the Cost of Memory Care: A State-by-State Guide*, A PLACE FOR MOM (Sept. 20, 2024), <https://www.aplaceformom.com/caregiver-resources/articles/cost-of-memory-care>.

<sup>21</sup> See generally *id.*

<sup>22</sup> Genworth, *Cost of Care, Financial Solutions for Long Term Care*, GENWORTH.COM (last visited Oct. 30, 2024), <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>. (understanding the cost of care is the first step to implementing a standard of care for patients who need long-term care).

<sup>23</sup> *Alzheimer’s and Dementia Care Costs: Facts & Figures*, SENIOR HOMES (last visited Oct. 21, 2023), <https://www.seniorhomes.com/alzheimers-care-costs/>.

<sup>24</sup> See *id.*

without the additional costs associated with customized therapies.<sup>25</sup> Staff-to-patient ratios, respectful treatment, communication, patient autonomy, and adequate facility resources must be considered when choosing a memory care community.<sup>26</sup>

However, without adequate funding, many are unable to afford even a fraction of the quality of care a patient with Alzheimer's or other types of dementia requires.<sup>27</sup> To pay for the type of long-term care they need, those diagnosed with dementia and their family members are generally on their own.<sup>28</sup> Medicaid sometimes fills the gaps in coverage left by the short, one-year period Medicare covers, but only if the individual has little to no assets or depletes their assets.<sup>29</sup> Some patients have private long-term-care policies that cover a portion of care, but this requires a level of foresight many diagnosed with Alzheimer's or other dementias do not have.<sup>30</sup> Additionally, as few as half of older individuals with dementia (and their families) have guidance from healthcare providers or social workers on the services available to them post-diagnosis.<sup>31</sup> Clearly, lack of guidance and availability of adequate information only exacerbates the barriers to accessing care for these individuals. This system locks people out by failing to provide basic support and communication, which only results in poor quality of care.

### *B. Medicaid*

Memory care facility costs can vary from state to state, even from facility to facility in the same area.<sup>32</sup> Oftentimes, seniors find that the cost of memory care is prohibitively high without additional support.<sup>33</sup> Some seniors may qualify for Medicaid assistance to supplement the cost of living in a long-term care facility. In most states, a single individual 65 years or older qualifies for Medicaid

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<sup>25</sup> Payton Sy, *What Nursing Home 'Memory Care' Means*, U.S. NEWS (Aug. 21, 2024), <https://health.usnews.com/health-news/patient-advice/articles/2016-06-01/what-nursing-home-memory-care-means>.

<sup>26</sup> *Id.*; see generally Beauchamp & Childress, *supra* note 8.

<sup>27</sup> See *Paying for Alzheimer's Care*, MEMORY CARE.COM (last visited Oct. 30, 2024), <https://www.memorycare.com/paying-for-alzheimers-care/>.

<sup>28</sup> Ellen Stark, *Long-Term-Care Insurance Gets a Makeover*, CONSUMER REP. (Aug. 31, 2017), <https://www.consumerreports.org/long-term-care-insurance/long-term-care-insurance-gets-a-makeover/>.

<sup>29</sup> *Id.*

<sup>30</sup> *Id.*

<sup>31</sup> Regina Shih, et al., *Improving Dementia Long-Term Care*, 4 RAND HEALTH Q. (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5051994/>.

<sup>32</sup> *E.g.*, Kemp, *supra* note 16.

<sup>33</sup> *Does Medicaid Pay for Memory Care?*, MEMORY CARE.COM (last visited Oct. 21, 2023), <https://www.memorycare.com/does-medicaid-pay-for-memory-care/>.

assistance if their income is less than \$2,829 a month.<sup>34</sup> In addition to the financial threshold, there is also a functional “level of care” requirement to qualify for long-term care through Medicaid, which requires the applicant to need the level of care sought.<sup>35</sup> Typically, the progression of symptoms of Alzheimer’s and other dementias will render an applicant eligible but a mere medical diagnosis does not, by itself, lead to a determination that an individual meets Medicaid’s “level of care” requirements.<sup>36</sup>

Many states have waivers allowing seniors to receive long-term care in memory care facilities, which helps states reduce their Medicaid costs.<sup>37</sup> However, the waiver programs are not entitlement programs and require applications, which can delay access to care.<sup>38</sup> The patients may be placed on a waiting list until a spot becomes available, while their cognitive health continues to decline.<sup>39</sup> It is important to note that the waiver programs do not cover all costs in memory care facilities, leaving individuals to rely on other funding to cover added costs of room and board.<sup>40</sup> For low-income individuals who exceed the asset threshold but lack sufficient resources to afford long-term care, the barrier to access care looms larger. When people are unable to access the necessary care, they are forced to remain in society, where they potentially become a community burden or are left isolated in their suffering.<sup>41</sup>

### C. Medicare

Some individuals are enrolled in a Medicare program that can help cover some costs for memory care.<sup>42</sup> Medicare never covers any type of long-term care so strategic planning is often necessary to properly utilize Medicare assistance.<sup>43</sup> Medicare Part A provides limited coverage for up to 100 days in a skilled nursing

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<sup>34</sup> *Medicaid Eligibility: 2023 Income, Asset & Care Requirements for Nursing Homes & Long-Term Care*, AM. COUNCIL ON AGING (Jan. 29, 2024),

<https://www.medicaidplanningassistance.org/medicaid-eligibility/#:~:text=their%20countable%20assets,-.Income%20Eligibility%20Criteria,through%20a%20state's%20HCBS%20Waivers.>

<sup>35</sup> *Id.*

<sup>36</sup> *Id.*

<sup>37</sup> MEMORY CARE, *supra* note 33.

<sup>38</sup> *See id.*

<sup>39</sup> *Id.*

<sup>40</sup> *Id.*

<sup>41</sup> *Cf.*, Amy Kelley, et al., *The Burden of Health Care Costs in the Last Five Years of Life*, 163 ANNALS INTERNAL MED. NO. 10, 729-36 (2015), <https://pmc.ncbi.nlm.nih.gov/articles/PMC4809412/> (examining the social costs of dementia).

<sup>42</sup> *Does Medicare Cover Memory Care Facilities?*, MEMORY CARE.COM (last visited Oct. 30, 2024), <https://www.memorycare.com/does-medicare-cover-memory-care/>.

<sup>43</sup> *Id.*

facility; however, deductibles, coinsurance, and copayments will still need to be paid.<sup>44</sup> Medicare also has many conditions a person needs to meet to receive coverage for nursing home stays; the covered services are specific and limited in scope.<sup>45</sup> The Annals of Internal Medicine Health and Retirement Study data shows that health care for Medicare beneficiaries in the last five years of life required significantly higher out-of-pocket costs for dementia patients than for those with heart disease, cancer, or other conditions.<sup>46</sup> “Out-of-pocket costs averaged \$62,000 for people with dementia, more than 80% higher than for someone with heart disease or cancer.”<sup>47</sup> If the patient exceeds the coverage period and runs out of funds, they risk eviction and loss of care.<sup>48</sup>

Some states offer the Program of All-Inclusive Care for the Elderly (PACE) which combines Medicare and Medicaid services and covers medical, social services, and long-term care costs.<sup>49</sup> PACE may pay for long-term care needs for persons with Alzheimer’s or other dementias, but a person must qualify for PACE by living in a PACE service area.<sup>50</sup> Requirements to qualify for PACE are extremely particular and a person must show a need for nursing home-level care and may have to pay a monthly premium for long-term care and Medicare Part D drug plans if they do not qualify for Medicaid but have Medicare.<sup>51</sup> While PACE covers most prescription drugs, enrollment in a separate Medicare drug plan while in the program will result in disenrollment from PACE.<sup>52</sup> PACE is only available in certain states that offer the program under their state Medicaid program.<sup>53</sup>

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<sup>44</sup> *Skilled Nursing Facility (SNF) Care*, MEDICARE.GOV (last visited Oct. 30, 2024), <https://www.medicare.gov/coverage/skilled-nursing-facility-snf-care>; *Understanding Medicare & Medicaid*, GENWORTH (last visited Oct. 21, 2023), <https://www.genworth.com/aging-and-you/finances/limits-of-medicare-medicaid>.

<sup>45</sup> MEDICARE.GOV, *supra* note 44.

<sup>46</sup> Kelley, *supra* note 41.

<sup>47</sup> Mark Mather & Paola Scommegna, *The Demography of Dementia and Dementia Caregiving*, POP. REF. BUREAU (May 28, 2020), <https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/>.

<sup>48</sup> Assisting Hands, *What Happens if Seniors Have No Money?*, ASSISTING HANDS HOME CARE (Jan. 24, 2023), <https://assistinghands.com/55/florida/sarasota/blog/seniors-with-no-money/>.

<sup>49</sup> PACE, MEDICARE.GOV (last visited Oct. 30, 2024), <https://www.medicare.gov/health-drug-plans/health-plans/your-coverage-options/other-medicare-health-plans/PACE>.

<sup>50</sup> *Paying for Long-Term Care*, NAT’L INST. ON AGING (last visited Oct. 30, 2024), <https://www.nia.nih.gov/health/paying-long-term-care>.

<sup>51</sup> MEDICARE.GOV, *supra* note 44.

<sup>52</sup> *Id.*

<sup>53</sup> *Id.*

#### D. Private Funding

Private long-term care insurance plans are designed to cover the costs of services required to assist patients who cannot perform activities essential to daily living.<sup>54</sup> Policyholders pay a monthly or annual premium to receive coverage for nursing home services.<sup>55</sup> However, these premiums are often high and increase over time.<sup>56</sup> Depending on financial resources, long-term care insurance may be unaffordable for those unable to keep up with rising premiums.<sup>57</sup> Factors including age, health status, gender, marital status, level of care, and optional add-on choices all play a role in pricing a long-term care insurance plan.<sup>58</sup> Memory-care services almost certainly will result in care that costs higher than the average long-term care costs.<sup>59</sup> Furthermore, the ideal time to buy long-term care insurance is in a person's mid-50s to early 60s, which requires planning before any diagnosis or need is apparent.<sup>60</sup> Additionally, persons already in poor health, such as those with Alzheimer's, may not qualify for long-term care insurance.<sup>61</sup> Long-term care insurance has also never been more expensive and "middle-income people have essentially been priced out."<sup>62</sup> Even for those who do purchase long-term care insurance, the policies frequently lapse due to financial struggle or cognitive decline.<sup>63</sup>

According to the Alzheimer's Association annual report, "more than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias."<sup>64</sup> Informal caregivers, most often family members or friends, front large out-of-pocket costs for the care of a person with a form of dementia.<sup>65</sup> The availability and involvement of family members directly influence the type of

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<sup>54</sup> Shawn Plummer, *Understanding Traditional Long-Term Care Insurance*, THE ANNUITY EXPERT (last visited Oct. 30, 2024), <https://www.annuityexpertadvice.com/types-of-annuities/long-term-care-annuity/>.

<sup>55</sup> *Id.*

<sup>56</sup> *Id.*

<sup>57</sup> *Id.*

<sup>58</sup> Danny Szlauderbach, *Long-Term Care Insurance: An In-Depth Guide and Options for 2023*, A PLACE FOR MOM (Oct. 10, 2024), <https://www.aplaceformom.com/caregiver-resources/articles/senior-care-insurance>; *Long-Term Care Insurance Facts - Data - Statistics - 2022 Reports*, AM. ASS'N FOR LONG-TERM CARE INS. (2022), <https://www.aaltci.org/long-term-care-insurance/learning-center/lcfacts-2022.php#2022costs>.

<sup>59</sup> Szlauderbach, *supra* note 58.

<sup>60</sup> Plummer, *supra* note 54.

<sup>61</sup> See NAT'L INST. ON AGING, *supra* note 50.

<sup>62</sup> Stark, *supra* note 28.

<sup>63</sup> *Id.*

<sup>64</sup> *2024 Alzheimer's Disease Facts and Figures Special Rep.*, ALZHEIMER'S ASS'N 41 (April 30, 2024) <https://alzjournals.onlinelibrary.wiley.com/doi/10.1002/alz.13809>.

<sup>65</sup> *Id.* at 50.

care received by individuals with dementia.<sup>66</sup> Financial, emotional, mental, and physical burdens often drive caregivers to seek long-term care facilities for a person with dementia.<sup>67</sup> People with dementia frequently rely on family care to maintain their health and sense of self.<sup>68</sup> Specifically, those in the middle class face the unique challenge of relying solely on caregivers, paying out of pocket, or exhausting their assets until they become eligible for Medicaid assistance.<sup>69</sup> Long-term care insurance can help ease caregiver burden for those who qualify and can afford a plan.<sup>70</sup>

However, individuals with minimal to no family or financial support can become wards of the state, and a case manager will be appointed to make decisions about their living situation.<sup>71</sup> Frequently, the individual is placed in a care facility where abuse is an unfortunate reality.<sup>72</sup> State case managers are often overloaded with clients and do not have time to evaluate the detailed personal needs of a patient with dementia, which means that memory care patients often go without the level of crucial specialized care.<sup>73</sup> Further, average direct care workers make between \$11 and \$12 an hour, lower than the minimum wage in some states.<sup>74</sup> These low wages lead to high turnover in care staff which can result in a lack of incentive to provide the highest standard of care.<sup>75</sup> However, higher wages alone cannot fix our morally broken world. Most times, money is not enough incentive to ensure older individuals with dementia are properly cared for and treated as valuable.<sup>76</sup> Accessing quality care for those with Alzheimer's and other dementias should not be difficult. Professional care in long-term care facilities should not be considered a last resort or made inaccessible due to financial limitations. Quality care should not be reserved only for those with wealth. An ideal society would prioritize access to long-term professional care for this vulnerable group because it feels a moral duty to ensure all can participate in virtuous living.

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<sup>66</sup> See Mather & Scommegna, *supra* note 47.

<sup>67</sup> ALZHEIMER'S ASS'N, *supra* note 64, at 48.

<sup>68</sup> *Id.*

<sup>69</sup> Mather & Scommegna, *supra* note 47.

<sup>70</sup> Szlauderbach, *supra* note 58.

<sup>71</sup> Assisting Hands, *supra* note 48.

<sup>72</sup> Robrt Pela, *Why Some Adults with Developmental Disabilities Become Wards of the State*, NEXT AVENUE (June 6, 2022), <https://www.nextavenue.org/adults-with-disabilities-ward-of-state/>.

<sup>73</sup> *Id.*

<sup>74</sup> *Id.*

<sup>75</sup> *Id.*

<sup>76</sup> *Id.*



### III. THE NURSING HOME STANDARD OF CARE

#### A. Nursing Home Reform Law

The exact definition of the applicable nursing home standard of care varies by state, but the consensus is based on “guidelines a competent healthcare professional in the field can reasonably be expected to meet.”<sup>77</sup> Ambiguities in terms such as “competent,” “professional,” and “reasonably,” provide little to no guidance for the ordinary individual in recognizing care that falls below the standard. Congress enacted the Nursing Home Reform Act in 1987 which established that nursing homes “must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.”<sup>78</sup> To receive funding from Medicare and Medicaid, nursing home facilities must comply with federal nursing home regulations.<sup>79</sup> Certified nursing homes receiving Medicare or Medicaid payments are governed by the Nursing Home Reform Law (Reform Law).<sup>80</sup> The Reform Law requires nursing homes to have “sufficient” nursing staff with appropriate competencies and skills to meet residents’ needs.<sup>81</sup> Nursing homes must meet the “sufficient staff” requirement on a 24-hour basis and are required to post daily nurse staffing data, including the total number of staff, types of staff, and the actual hours worked by each staff member.<sup>82</sup> Additionally, most states have established their own minimum nursing home staffing requirements.<sup>83</sup>

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<sup>77</sup> Cardinal LifeCare Consulting, *What is the Nursing Home Standard of Care*, CARDINAL LIFECARE CONSULTING (Mar. 22, 2021), [https://cardinallifecare.com/nursing-home-standard-of-care/#:~:text=Provide%20residents%20with%20adequate%20nutrition,meal%20schedules%2C%20etc.\)%3B%20and](https://cardinallifecare.com/nursing-home-standard-of-care/#:~:text=Provide%20residents%20with%20adequate%20nutrition,meal%20schedules%2C%20etc.)%3B%20and).

<sup>78</sup> 42 U.S.C. § 1395i-3(b)(2); *Nursing Home Reform: Where Are We Now? Where Do We Need to Go?*, CTR. FOR MEDICARE ADVOCACY (Dec. 1, 2022), <https://medicareadvocacy.org/nursing-home-reform-where-are-we-now-where-do-we-need-to-go/#:~:text=A%20major%20success%20is%20the,those%20assessments%2C%20and%20much%20more>.

<sup>79</sup> *Federal Nursing Home Regulations and State Laws*, NURSING HOME ALERT (last visited Oct. 30, 2024), <https://www.nursinghomealert.com/federal-nursing-home-regulations-and-state-laws>.

<sup>80</sup> Eric Carlson, *25 Common Nursing Home Problems & How to Resolve Them*, JUST. IN AGING (Jan. 2024), [https://www.justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them\\_Final.pdf?\\_gl=1\\*fjz9v\\*\\_ga\\*MTcxNDk3NzI3LjE2OTM4MzY1OTc.\\*\\_ga\\_MM4QDHFHG\\_L\\*MTY5MzgzMzU5Ni4xLjAuMTY5MzgzMzU5Ni42MC4wLjA](https://www.justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them_Final.pdf?_gl=1*fjz9v*_ga*MTcxNDk3NzI3LjE2OTM4MzY1OTc.*_ga_MM4QDHFHG_L*MTY5MzgzMzU5Ni4xLjAuMTY5MzgzMzU5Ni42MC4wLjA).

<sup>81</sup> 42 U.S.C. § 1395i-(b)(4)(C)(8).

<sup>82</sup> *Id.*

<sup>83</sup> Charlene Harrington, et al., *Appropriate Nurse Staffing Levels for U.S. Nursing Homes*, 13 HEALTH SERV. INSIGHTS (2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7328494/>.

## B. Current Developments

In 2016, the Centers for Medicare and Medicaid Services (CMS) established regulations that require nursing homes to conduct a self-assessment of their facilities, considering “the number, acuity, and diagnoses of the facility’s resident population” to establish what resources are needed to meet patient needs.<sup>84</sup> The assessment must be conducted using several informational sources such as the residents, family members, representatives, and others.<sup>85</sup> Nursing Homes are required to submit daily staffing to CMS on a Payroll Based Journal (PBJ) reporting system quarterly.<sup>86</sup> Analysis of the PBJ data showed that nursing home staffing frequently fell below CMS expectations.<sup>87</sup> Based on PBJ data in 2019, the “average nursing home reported total nurse staffing levels of 3.89 hours per resident day.”<sup>88</sup>

In June of 2022, CMS issued guidance to implement standards of care for nursing homes, first promulgated in 2016 and delayed due to the COVID-19 pandemic.<sup>89</sup> The CMS Guidelines are for government inspectors to use when determining “whether and to what extent a nursing facility has violated federal requirements.”<sup>90</sup> The Guidance details that “compliance with state-law staffing minimums does not necessarily meet the federal requirement of sufficient

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<sup>84</sup> Medicare and Medicaid Programs: Reform of Requirements for Long-Term Care Facilities Final Rule, 42 C.F.R. § 483.25 (2016).

<sup>84</sup> 42 C.F.R. § 483.35 (2016).

<sup>85</sup> *Id.*

<sup>86</sup> *Staffing Data Submission Payroll Based Journal (PBJ)*, CMS.GOV (2017), <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Staffing-Data-Submission-PBJ.html>.

<sup>87</sup> Fangli Geng, et al., *Daily Nursing Home Staffing Levels Highly Variable, Often Below CMS Expectations*, 38 HEALTH AFF. 1095–1100 (2019), <https://pubmed.ncbi.nlm.nih.gov/31260368/>.

<sup>88</sup> Charlene Harrington, et al., *Appropriate Nurse Staffing Levels for U.S. Nursing Homes*, 13 HEALTH SERV. INSIGHTS (2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7328494/>; A calculation of nursing hours per resident day is comprised of the total number of direct care nursing staff hours worked by each person for every 24-hour period divided by the total number of residents in the facility; see ShiftMed Team, *How to Optimize Your HPPD Goal for Healthcare Excellence*, SHIFTMED.COM (Oct. 10, 2023), <https://www.shiftmed.com/blog/how-to-effectively-manage-your-hppd-goal/#:~:text=What%20is%20HPPD%3F,of%20patients%20in%20the%20facility>.

<sup>89</sup> T. Edelman, *CMS Acts to Implement Revised Nursing Home Standards of Care*, CTR. FOR MEDICARE ADVOC. (July 7, 2022), <https://medicareadvocacy.org/cms-acts-to-implement-revised-nursing-home-standards-of-care/> (stating that facilities with higher hours per resident day scores generally have better patient outcomes and satisfaction rates; these outcomes are due to better care resulting from more time and attention devoted to each patient).

<sup>90</sup> Eric Carlson, *Understanding CMS’s New Nursing Facility Guidance*, JUST. IN AGING (2022), <https://justiceinaging.org/wp-content/uploads/2022/07/Understanding-CMSs-New-NF-Guidance-Issue-Brief.pdf>.

staffing.”<sup>91</sup> Surveyors use the PBJ data to identify dates when a nursing home facility may have failed to have sufficient staffing.<sup>92</sup> The Guidance provides that a nursing home resident “has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.”<sup>93</sup> The guidelines further explain that abuse includes “deprivation by an individual, including a caretaker, of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being.”<sup>94</sup> Nursing home management and staff have moral and legal duties to implement policies and act according to the standard of care.

#### IV. IT’S ABUSE AND WE KNOW IT

##### A. Inadequate Staffing

Older adults with dementia are highly dependent upon the staff at long-term care facilities, which creates an environment ripe for abuse.<sup>95</sup> A study by Dana Mukamel and colleagues found that only nursing homes with 90 percent of residents with Alzheimer’s and other dementias offered better care for those residents.<sup>96</sup> The quality of care can be impacted by the caregivers’ knowledge, attitudes, training, and perceptions regarding individuals with dementia.<sup>97</sup> According to a 2020 World Health Organization (WHO) study, over 66% of nursing home staff members admitted to committing some form of abuse or neglect.<sup>98</sup> WHO defines elder abuse as “a single, or repeated act, or *lack of appropriate action*, occurring with any relationship where there is an expectation

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<sup>91</sup> *Id.*

<sup>92</sup> *Id.*

<sup>93</sup> 42 C.F.R. § 483.13(b).

<sup>94</sup> Interpretive Guidelines, 42 C.F.R. § 483.13 (b) and (c); STATE OPERATIONS MANUAL: APPENDIX PP—GUIDANCE TO SURVEYORS FOR LONG TERM CARE FACILITIES, CMS.GOV (2017), [https://www.cms.gov/regulations-and-guidance/legislation/cfcsandcops/downloads/som107ap\\_pp\\_guidelines\\_ltcfpdf](https://www.cms.gov/regulations-and-guidance/legislation/cfcsandcops/downloads/som107ap_pp_guidelines_ltcfpdf).

<sup>95</sup> Yongie Yon, et al., *The Prevalence of Elder Abuse in Institutional Settings: A Systematic Review and Meta-Analysis*, 29 EUR. J. OF PUB. HEALTH 58–67 (2018), <https://academic.oup.com/eurpub/article/29/1/58/5033581?guestAccessKey=482da8b7-f9f4-4205-811d-0dd9788cddb1&login=false>.

<sup>96</sup> Dana Mukamel, et al., *Dementia Care is Widespread in U.S. Nursing Homes; Facilities with the Most Dementia Patients May Offer Better Care*, 42 HEALTH AFF. 795 (2023), <https://www.healthaffairs.org/doi/epdf/10.1377/hlthaff.2022.01263>.

<sup>97</sup> Sara Mahmoud Yaghmour, *Impact of Settings and Culture on Nurses’ Knowledge of and Attitudes and Perceptions Towards People with Dementia: An Integrative Literature Review*, 9 NURSES OPEN 66–93 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8685848/>.

<sup>98</sup> Julie Rivers, *Nursing Home Abuse Statistics*, NURSING HOME ABUSE CTR. (Mar. 15, 2024) <https://www.nursinghomeabuse.org/nursing-home-abuse/statistics/>.

of trust which causes harm or distress to an older person” (emphasis added).<sup>99</sup> Further research shows that about 10 percent of nursing home residents experience abuse or neglect.<sup>100</sup> Instances of nursing home abuse are also widely believed to be grossly underreported.<sup>101</sup> Many residents fear retaliation, suffer from feelings of embarrassment or shame, or are not physically or cognitively capable of reporting abuse themselves.<sup>102</sup> Other potential reporters, such as family members, are not often present to witness the abuse and frequently have no knowledge of the occurrence of abuse.<sup>103</sup> Therefore, without extensive monitoring and tracking systems in place, abuse in long-term care facilities often goes unnoticed and unreported.<sup>104</sup> A 2022 review of staff-to-resident abuse in nursing homes studies showed that abuse was considered “unacceptable,” but was underreported.<sup>105</sup>

Reporting abuse requires that participants “recognize abuse, recall past events, consider them worth reporting, and avoid socially desirable responses.”<sup>106</sup> But Alzheimer’s patients often do not remember or recognize signs of abuse or mistreatment, leaving nursing home staff with a moral duty to recognize, report, and prevent. According to a 2021 study by the American Health Care Association and National Center for Assisted Living (AHCA/NCAL), ninety-four percent of nursing homes reported staffing shortages.<sup>107</sup> Low staff wages and benefits contribute to poor job retention and higher turnover rates in long-term care facilities.<sup>108</sup> Underpaid nursing home staff and caregivers are more likely to be abusive towards a resident.<sup>109</sup> The understaffing and high turnover rates in long-term care facilities result in over-scheduling of staff members, who then

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<sup>99</sup> WHO, *Elder Abuse Fact Sheet 357*, Geneva: World Health Organization (2017) *Abuse of older people*, WORLD HEALTH ORG. (June 15, 2024) <https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people>.

<sup>100</sup> *Common is Nursing Home Abuse*, NURSING HOMES ABUSE.ORG (Apr. 14, 2023), <https://nursinghomesabuse.org/faqs/how-common-is-nursing-home-abuse/#:~:text=How%20prevalent%20is%20abuse%20in,to%20be%20victims%20of%20abuse>.

<sup>101</sup> *Id.*

<sup>102</sup> *Id.*

<sup>103</sup> *Id.*

<sup>104</sup> *Id.*

<sup>105</sup> Julian Hirt, et al., *Staff-to-Resident Abuse in Nursing Homes: A Scoping Review*, 22 BMC GERIATRICS 563 (2022), <https://link.springer.com/article/10.1186/s12877-022-03243-9>.

<sup>106</sup> *Id.*

<sup>107</sup> *Survey: 94 Percent of Nursing Homes Face Staffing Shortages*, AM. HEALTH CARE ASS’N & NAT’L CTR. FOR ASSISTED LIVING (June 23, 2021), <https://www.ahcancal.org/News-and-Communications/Press-Releases/Pages/Survey-94-Percent-of-Nursing-Homes-Face-Staffing-Shortages.aspx>.

<sup>108</sup> *See id.*

<sup>109</sup> *Understaffing in Nursing Homes*, NURSING HOME ABUSE CTR. (last visited Oct. 30, 2024), <https://www.nursinghomeabusecenter.com/nursing-home-neglect/understaffing/>.

frequently become overwhelmed by additional duties.<sup>110</sup> The cyclical pattern many nursing home staff members are locked in may increase the likelihood of abusive environments.<sup>111</sup> High resident-to-staff ratios further encourage abuse and neglect.<sup>112</sup> Understaffing at nursing homes can result in staff acting with impatience, using unnecessary force, and neglecting residents.<sup>113</sup>

A survey by the Agency for Healthcare Administrations (AHCA) showed that eighty-seven percent of the 759 homes surveyed had moderate to high levels of staffing shortages.<sup>114</sup> The top issue reported preventing the hiring of new staff was a “lack of interested or qualified” workers.<sup>115</sup> Due to staffing shortages, many facilities were forced to hire staff from agencies, which have much higher average costs.<sup>116</sup> Government regulations recently, as of June 2024, set a minimum staffing requirement for nursing home facilities.<sup>117</sup> In February 2022, President Biden proposed new reforms to ensure “every nursing home provides a sufficient number of staff who are adequately trained to provide high-quality care.”<sup>118</sup> These new reforms, now in effect, established a minimum nursing home staff requirement and CMS implemented “minimum standards for staffing adequacy that nursing homes must meet.”<sup>119</sup> However, without proper funding from Medicare and Medicaid, many of these proposed standards will be meaningless and unachievable.<sup>120</sup>

CMS is responsible for ensuring nursing home residents are free from abuse and the facilities are meeting federal quality standards through surveys and

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<sup>110</sup> *Id.*

<sup>111</sup> *See id.*

<sup>112</sup> *Id.*

<sup>113</sup> *See id.*

<sup>114</sup> State of the Nursing Home Industry: Survey of 759 Nursing Home Providers Show Industry Still Facing Major Staffing and Economic Crisis, AM. HEALTHCARE ASS’N (2022), <https://www.ahcancal.org/News-and-Communications/Fact-Sheets/FactSheets/SNF-Survey-June2022.pdf> [Ref list].

<sup>115</sup> *Id.*

<sup>116</sup> Cheryl Heiks & Nicole Sabine, *Long Term Care and Skilled Nursing Facilities*, 8 DEL. J. PUB. HEALTH 144–49 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9894029/>.

<sup>117</sup> 42 C.F.R. §§ 438, 442, 483.

<sup>118</sup> FACT SHEET: PROTECTING SENIORS BY IMPROVING SAFETY AND QUALITY OF CARE IN THE NATION’S NURSING HOMES, WHITE HOUSE.GOV (Feb. 28, 2022), <https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/>.

<sup>119</sup> *Id.*; 42 C.F.R. §§ 438, 442, 483.

<sup>120</sup> Jordan Rau, *Federal Officials Propose New Nursing Home Standards to Increase Staffing*, N.Y. TIMES (Sept. 1, 2023), <https://www.nytimes.com/2023/09/01/health/nursing-home-staffing-cms.html>.

investigations.<sup>121</sup> A U.S. Government Accountability Office (GAO) report of CMS data in 2017 found that “physical and mental/verbal abuse occurred most often in nursing homes” and “staff were more often the perpetrators of the abuse.”<sup>122</sup> As of February 2020, nursing homes are required to report to the state survey agency “reasonable suspicions of a crime that results in serious bodily injury to a resident,” and state survey agencies are required to make an immediate referral to law enforcement and Medicaid Fraud Control Units when they receive complaints.<sup>123</sup> In October 2022, CMS issued guidance instructing state agencies to immediately report suspected crimes to law enforcement and to enter data into CMS’s database for those referrals.<sup>124</sup> Owners and operators of nursing homes have little to no accountability for poor nursing home performance, leading to maltreatment and quality that falls far below the standard of care.<sup>125</sup> CMS is working to implement Affordable Care Act requirements for financial transparency to help protect nursing home residents, a measure that should have been in place long ago.<sup>126</sup> Despite the regulations and congressional efforts, there are still enormous gaps in quality care, resulting in detrimental harm to residents in long-term care facilities.<sup>127</sup>

CMS provides information to the public through Care Compare, a website featuring tools and a rating system to assess the safety and quality of thousands of certified nursing homes nationwide.<sup>128</sup> However, the rating system does not factor in reports that are “quashed during a secretive appeals process.”<sup>129</sup> The ratings do not accurately report how many nursing home residents are unnecessarily administered antipsychotic drugs.<sup>130</sup> Further, the inspection process utilized by the CMS rating system rarely gives an accurate representation of what goes on inside nursing homes. Inspectors' reports are often challenged by nursing homes through

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<sup>121</sup> U.S. Gov’t Accountability Off., GAO-19-433, *Nursing Homes: Improved Oversight Needed to Better Protect Residents from Abuse* (2019).

<sup>122</sup> *Id.*

<sup>123</sup> *Id.*

<sup>124</sup> Director, Quality, Safety & Oversight Group, *Revisions to the Special Focus Facility (SFF) Program*, Ref: QSO-23-01-NH, DEPT. OF HEALTH & HUMAN SERV., CMS (Oct. 21, 2022), <https://www.cms.gov/files/document/qso-23-01-nh.pdf>.

<sup>125</sup> WHITEHOUSE.GOV, *supra* note 118.

<sup>126</sup> *Id.*

<sup>127</sup> *Elder Mistreatment in Long-Term Care*, NAT’L CTR. ON ELDER ABUSE (NCEA) (2022), <https://drive.google.com/file/d/13cUkPQknbSTFYMQHhT-Syt0LuFfIG2Vp/view>.

<sup>128</sup> CARE COMPARE, <https://www.medicare.gov/care-compare/> (last visited Oct. 21, 2023).

<sup>129</sup> Robert Gebeloff, et al., *How Nursing Homes’ Worst Offenses Are Hidden From the Public*, N.Y. TIMES (Dec. 9, 2021, updated June 22, 2023), <https://www.nytimes.com/2021/12/09/business/nursing-home-abuse-inspection.html>.

<sup>130</sup> *Id.*; Katie Thomas, et al., *Phony Diagnoses Hide High Rates of Drugging at Nursing Homes*, N.Y. TIMES (Sept. 11, 2021, updated Oct. 15, 2021), <https://www.nytimes.com/2021/09/11/health/nursing-homes-schizophrenia-antipsychotics.html>.

a confidential appeals process in a specialized federal court within the executive branch.<sup>131</sup> This pattern empowers nursing homes to continue fostering environments of abuse and neglect. The secrecy of nursing home disparities further exacerbates abusive environments and inequities within long-term care facilities. Ultimately, nursing homes that operate in this secretive, negligent manner are failing to uphold their duty to safeguard their residents. A government that knows injustice is occurring and continues to sweep it under the giant rug provided by those who must ensure regulations are followed is an iniquitous one.

### *B. Memory Care Staff*

The need for Alzheimer's care workers is increasing, and the specific needs of patients require skilled healthcare professionals.<sup>132</sup> People with Alzheimer's who live in rural areas face tremendous barriers to accessing the specialized care they need.<sup>133</sup> According to the 2019 Alzheimer's Association survey, sixty-three percent of Primary Care Physicians (PCPs) in small cities and seventy-one percent of PCPs in rural areas reported there were not enough specialists in their area. Limited specialization in education and training for dementia care is another force contributing to the lack of individuals entering this area of the healthcare workforce.<sup>134</sup> As a result of significant gaps in the workforce supporting older adults living with dementia, the health outcomes of patients with dementia are often directly impacted.<sup>135</sup> Diagnoses of Alzheimer's disease and other dementias are frequently delayed due to the widespread shortage of geriatricians and other specialists, and patients are unable to seek the care and support they need.<sup>136</sup> Training professionals to specialize in targeted dementia care and expanding the workforce are essential steps to bring about change/ drive meaningful improvements in long-term care<sup>137</sup>

Cognitive impairment from Alzheimer's and other dementias often prevents patients from recognizing and communicating their needs, leaving them unable to advocate for themselves. Without family members who can visit frequently, nursing home residents with dementia face the possibility of not being turned, fed, changed, or otherwise cared for properly.<sup>138</sup> Many nursing home residents with dementia are administered prescription antipsychotic drugs to

<sup>131</sup> Gebeloff, *supra* note 129.

<sup>132</sup> See ALZHEIMER'S ASS'N, *supra* note 64, at 57.

<sup>133</sup> *Id.* at 62.

<sup>134</sup> *Id.*

<sup>135</sup> *Id.*

<sup>136</sup> *Id.*

<sup>137</sup> *Id.* at 62-65.

<sup>138</sup> See HUM. RTS. WATCH, "They Want Docile" How Nursing Homes in the United States Overmedicate People with Dementia (2018).

control common symptoms of their disease.<sup>139</sup> The GAO reported, based on data from Medicare Part D (Medicare’s prescription drug program), that about “one-third of older adult[s] . . . with dementia who spent more than 100 days in a nursing home were prescribed an antipsychotic in 2012.”<sup>140</sup> According to a Human Rights Watch Report, these drugs are often given without informed consent since most of the individuals have Alzheimer’s disease or other related dementias.<sup>141</sup> The U.S. Food and Drug Administration (FDA) has not approved any antipsychotic drugs for treating dementia-related symptoms, and studies find that these drugs almost double the risk of death in people with dementia.<sup>142</sup>

Antipsychotic drugs are used by nursing home staff out of convenience to control difficult-to-manage dementia patients.<sup>143</sup> Human Rights Watch reported that “one of the most common ‘behaviors’ leading to antipsychotic drug prescriptions was someone constantly crying out, ‘help me, help me, help me.’”<sup>144</sup> The Alzheimer’s Society says that antipsychotic drugs should be given to dementia patients as a last resort and “with the utmost care, under constant supervision and with regular review.”<sup>145</sup> Moreover, antipsychotics can further exacerbate common symptoms of dementia such as confusion, memory trouble, or unsteadiness, and can increase risks of infections, falls, blood clots, strokes, and even death.<sup>146</sup> The GAO reported that nursing homes with lower staff numbers resulted in higher antipsychotic drug use.<sup>147</sup> The White House, in February 2022, acknowledged that “inappropriate diagnoses and prescribing” of antipsychotic drugs “still occur at too many nursing homes.”<sup>148</sup> CMS, in its 2022 Guidance, noted that it was “aware of situations where practitioners have potentially misdiagnosed residents with a condition for which antipsychotics are an approved

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<sup>139</sup> U.S. Gov’t Accountability Off., GAO-15-211, *Antipsychotic Drug Use: HHS Has Initiatives to Reduce Use Among Older Adults in Nursing Homes but Should Expand Efforts to Other Settings* at 1 (2015), <https://www.gao.gov/products/gao-15-211>.

<sup>140</sup> *Id.* at 10.

<sup>141</sup> HUM. RTS. WATCH, *supra* note 138, at 1.

<sup>142</sup> *Id.*; The FDA has a boxed warning that antipsychotic drugs may cause increased risk of death when used by older adults with dementia. See *FDA Analysis Finds No New or Unexpected Safety Risks Associated with Nuplazid (pimavanserin), A Medication to Treat the Hallucinations and Delusions of Parkinson’s Disease Psychosis*, U.S. FOOD & DRUG ADMIN. (Sept. 20, 2018), <https://www.fda.gov/drugs/drug-safety-and-availability/fda-analysis-finds-no-new-or-unexpected-safety-risks-associated-nuplazid-pimavanserin-medication>.

<sup>143</sup> HUM. RTS. WATCH, *supra* note 138, at 4.

<sup>144</sup> *Id.*

<sup>145</sup> *Antipsychotics and Other Drug Approaches in Dementia Care*, ALZHEIMER’S SOC’Y (last visited Oct. 30, 2024), <https://www.alzheimers.org.uk/about-dementia/treatments/drugs/antipsychotic-drugs>.

<sup>146</sup> *Id.*

<sup>147</sup> U.S. Gov’t Accountability Off., *supra* note 139, at 24.

<sup>148</sup> WHITE HOUSE.GOV, *supra* note 118.



use (e.g., new diagnosis of schizophrenia) [in order to] exclude the resident from the long-stay antipsychotic quality measure,” acknowledging misdiagnosis to justify antipsychotic drug use on nursing home residents.<sup>149</sup> By allowing the known maltreatment of dementia patients to exist, the U.S. is failing to ensure that one of our most vulnerable populations is protected.

Psychosocial harm is assessed on a “reasonable person” standard, “by asking how much harm a ‘reasonable person’ would have suffered as a result of the abuse in question.”<sup>150</sup> The CMS 2022 Guidance clarifies that, although a resident with dementia may not express outward feelings about incidents of abuse, the severity of the abuse is not reduced by lack of expression.<sup>151</sup> The Guidance explains that “a citation for neglect would require additional evidence that identifies that the facility knew, or should have known, to provide the staff, supplies, services, policies, training, or staff supervision and oversight to meet the resident’s needs, but continued to fail to take action necessary to avoid the potential for harm, or actual harm to the resident.”<sup>152</sup> Thus, “neglect” is not an automatic finding of resident abuse, and further evidence is needed to prove facilities’ knowledge of violations.<sup>153</sup> Residents, family members, and advocates have a moral obligation to call to attention events of abuse and neglect of nursing home residents.<sup>154</sup>

Nursing homes in the United States are predominantly for-profit (approximately sixty-nine percent) and engage in practices such as transferring residents to new beds as a way to receive the maximum amount of federal funding.<sup>155</sup> Patients funded by Medicare can be placed in a Medicare-certified bed, but when the funding ends, the patients are often kicked out of the bed to make room for another Medicare-funded resident.<sup>156</sup> However, nursing homes are frequently more finance-focused than person-centered and these transferring practices are far too common.<sup>157</sup> The focus of care must be based on the resident's needs, not the nursing home's finances. However, many nursing home staff

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<sup>149</sup> 42 C.F.R. § 483.10(c)(3), (e); Carlson, *supra* note 90, at 9.

<sup>150</sup> Carlson, *supra* note 90, at 10.

<sup>151</sup> *Id.*

<sup>152</sup> *Id.*; 42 C.F.R. § 483.12.

<sup>153</sup> Carlson, *supra* note 90, at 11.

<sup>154</sup> *Id.* at 12.

<sup>155</sup> NCEA, *supra* note 127, at 4; Eric Carlson, *25 Common Nursing Home Problems and How to Resolve Them*, JUST. IN AGING 39 (2022), [https://www.justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them-Final.pdf?\\_gl=1\\*fjz9v\\*\\_ga\\*MTcxNDk3NzI3LjE2OTM4MzY1OTc.\\*\\_ga\\_MM4QDHFHG L\\*MTY5MzgzMzU5Ni4xLjAuMTY5MzgzMzU5Ni42MC4wLjA](https://www.justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them-Final.pdf?_gl=1*fjz9v*_ga*MTcxNDk3NzI3LjE2OTM4MzY1OTc.*_ga_MM4QDHFHG L*MTY5MzgzMzU5Ni4xLjAuMTY5MzgzMzU5Ni42MC4wLjA).

<sup>156</sup> *Id.* at 39.

<sup>157</sup> *See id.* at 12.

members are making equal to or just above minimum wage, leaving very little financial incentive to deliver a higher standard of care.<sup>158</sup> The New York Times recently reported that many nursing home staff can choose to work in a hospital and “make more and do less” than in nursing homes.<sup>159</sup>

Nursing homes are required to develop policies to prevent mistreatment of residents, as well as assure adequate staffing.<sup>160</sup> Adequate staff-to-resident ratios are crucial for quality memory care and those staff members must be trained to know how to effectively care for Alzheimer’s and dementia patients.<sup>161</sup> Further, for-profit nursing homes are frequently associated with “poor quality of care and lower staffing levels, factors which are predictive of abuse.”<sup>162</sup> According to the National Center on Elder Abuse (NCEA), for-profit facilities generally provide a lower quality of care (when compared to non-profit ownership), due to “strategies for maximizing profits,” such as inadequate staffing.<sup>163</sup>

### C. *Ethics of Care*

It is estimated that forty percent of the global costs of dementia care in 2018 were devoted to informal care.<sup>164</sup> Informal caregivers take on enormous amounts of physical, emotional, social, and financial burden to care for someone with dementia, seemingly out of feelings of moral obligation.<sup>165</sup> Anecdotal evidence of informal caregivers unable to continue providing care suggests that long-term professional care is undesirable or the last choice for most.<sup>166</sup> But professional care *should* be the first choice, the *obvious* choice. Unfortunately, in our non-ideal world, injustices in professional care are too familiar and care is frequently inadequate. Placing someone in long-term care environments could arguably be considered committing grave harm when we know the actively unjust nature of care in long-term care facilities. This may deter people, who feel they have a moral duty to care for someone with Alzheimer’s or other dementias, to

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<sup>158</sup> See Rau, *supra* note 120.

<sup>159</sup> *Id.*

<sup>160</sup> NCEA, *supra* note 127, at 4; 42 C.F.R. § 483.10.

<sup>161</sup> Sy, *supra* note 5.

<sup>162</sup> NCEA, *supra* note 127, at 4.

<sup>163</sup> *Id.*

<sup>164</sup> Anders Wimo, et al., *Global Estimates of Informal Care*, ALZHEIMER’S DISEASE INT’L AND KAROLINSKA INST. 1, 6 (2018), <https://www.alzint.org/u/global-estimates-of-informal-care.pdf>.

<sup>165</sup> See Matilda Carter, *The Imperative of Professional Dementia Care*, 37 BIOETHICS 292–302 (2022).

<sup>166</sup> See Benedicte Carlsen & Kjetil Lundberg, ‘If it Weren’t for Me...’: Perspectives of Family Carers of Older People Receiving Professional Care, 32 SCAND. J. CARING SCI. 213–221 (2018); Janelle Jacobson, et al., Carers’ Experiences When the Person for Whom They Have Been Caring Enters a Residential Aged Care Facility Permanently: A Systematic Review, JBI DATABASE SYS. REV. IMPLEMENT REP. 241–317 (2015).

provide informal at-home care, despite the costs and despite lack of proper training or knowledge. However, preventing dementia patients from receiving professional, necessary care is harmful in itself. Thus, we are faced with a moral balancing game when assessing care.<sup>167</sup> In ideal circumstances, where nursing home (or other long-term facility) care is a just and adequate institutional system, we act unjustly by providing any other type of informal care because it frequently results in the person with Alzheimer’s or other dementias being worse off.

Institutional inadequacy and unjust practices in long-term care facilities expose persons with Alzheimer’s or other dementias to injustices they wouldn’t otherwise experience. A patient should not be denied necessary care just because their Medicare coverage limit has been reached.<sup>168</sup> Persons with Alzheimer’s disease and other dementias should receive necessary care independent of source of payment or number of resources.<sup>169</sup> Profit-focused nursing homes endanger patients who lose their “desirability” due to a lack of preferred or substantial funding methods.<sup>170</sup>

While the Reform Law gives residents the right to refuse a transfer within the facility if the purpose is to move out of a Medicare-certified bed to convenience the facility, the practice is still far too common and many residents are unaware of their ability to refuse.<sup>171</sup> Moral status is not earned based on being a certain “level” of human, and all humans have rights simply based on their personhood. An ideally just, civilized society ought to be protecting its most vulnerable members from abuse.

According to the NCEA, research on the “prevalence of elder abuse and neglect in nursing homes” is scarce.<sup>172</sup> However, self-reported data from residents, families, staff, and other anecdotal accounts suggest that abuse may be widespread.<sup>173</sup> Research is lacking because often we don’t *want* to address these issues—if they don’t affect us, why bother? The NCEA reported that from 2013 to 2017, “the number of CMS deficiency citations for serious mistreatment more than doubled, even though the total number of citations decreased.”<sup>174</sup> However, remediating abuse through citations for deficiency frequently fails because for-

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<sup>167</sup> See generally Patricia Lindeza, et al., *Impact of Dementia on Informal Care: A Systematic Review of Family Caregivers’ Perceptions*, BMJ SUPPORTIVE & PALLIATIVE CARE E38, E43 (2020), <https://spcare.bmj.com/content/early/2022/08/21/bmjspcare-2020-002242>.

<sup>168</sup> Carlson, *supra* note 80, at 38.

<sup>169</sup> *Id.* at 10.

<sup>170</sup> *Id.* at 39.

<sup>171</sup> 42 C.F.R. § 483.10(f)(4) (2023).

<sup>172</sup> See NCEA, *supra* note 127, at 2.

<sup>173</sup> *Id.*

<sup>174</sup> *Id.*

profit homes consider these fines a “cost of doing business.”<sup>175</sup> Greater transparency regarding nursing home financing and corporate structure is necessary to ensure quality resident care.<sup>176</sup> Where is the justice in a society where abuse of vulnerable people is ignored in exchange for financial gain? To flourish, *all* individuals must be guaranteed some higher standard of existence. This higher standard includes fair protection of our most vulnerable. Society would thrive if patients with Alzheimer’s and other dementias received proper care and if the organizations responsible for their well-being adhered to the standards set by legislation.

I am encouraging a partially deontological approach to ethics in long-term care.<sup>177</sup> There are rules in place to ensure nursing homes are properly adhering to the standard of care.<sup>178</sup> We must follow the rules, develop policies, and implement that standard. In simpler terms, we are not necessarily confined by *rules* when faced with being morally good. We must only treat others with characteristics reflective of human decency. In doing so, we confront the moral dilemmas discussed above head-on, without any “balancing” necessary. By enforcing existing rules, developing more stringent policies, and implementing the standards of care, we largely eliminate the need to choose between outcomes that all fall short of the care these patients deserve.

## V. WHAT DOES GOOD LOOK LIKE

The Hogeweyk is a Dutch village aimed at revolutionizing dementia care.<sup>179</sup> The Hogeweyk provides a community for dementia patients to implement their mission of the “deinstitutionalization of care and the need to emancipate people living with dementia and include them in society.”<sup>180</sup> All residents of The Hogeweyk have some form of dementia.<sup>181</sup> The residents live together in groups of six with private rooms, shared common living spaces, and a personalized caregiver in each home.<sup>182</sup> This village structure allows residents to roam freely in

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<sup>175</sup> *Id.* at 4.

<sup>176</sup> *Id.*

<sup>177</sup> Beauchamp & Childress, *supra* note 8, at 394–400.

<sup>178</sup> 42 C.F.R. § 483.10 (2023).

<sup>179</sup> DEMENTIA VILLAGE ASSOCS. (last visited Oct. 30, 2024),

<https://hogeweyk.dementiavillage.com>.

<sup>180</sup> *Id.*

<sup>181</sup> See Ayun Halliday, *How a Dutch ‘Dementia Village’ Improves Quality of Life with Intentional Design*, OPEN CULTURE (Aug. 23, 2022), <https://www.openculture.com/2022/08/how-a-dutch-dementia-village-improves-quality-of-life-with-intentional-design.html>.

<sup>182</sup> *Id.*

the village and retain a sense of living in a community.<sup>183</sup> The village model allows for twenty-four-hour monitoring and care while leaving residents with autonomy and a sense of independence as they carry out “normal” daily activities.<sup>184</sup> The Hogeweyk utilizes a high staff-to-resident ratio, twice as many caregivers as residents, to ensure the highest level of care possible.<sup>185</sup> The staff dress in “ordinary” clothes and help the residents with accomplishing daily tasks.<sup>186</sup> Treating residents with dementia as normally as possible proves that residential dementia care can be integrated with normal societal functions.<sup>187</sup> The New York Times reported that these types of facilities “act as stepping stones for integrating those living with dementia into society at large.”<sup>188</sup>

Dementia “villages” have gained popularity throughout European countries.<sup>189</sup> In countries across Europe, where socialized medicine pays for most of the care, the incentive to develop more “dementia villages” is high.<sup>190</sup> The cost for these types of facilities would be the largest barrier to access in the United States where we rely on a private-paying market.<sup>191</sup> Costs for a facility of this type would fall “primarily on individuals rather than governments,” and many low or middle-income individuals would be unable to achieve this level of care.<sup>192</sup> Once again, quality care for people living with Alzheimer’s disease or other dementias in the United States would be out of reach without the proper financial resources.

These “villages” serve as an example of good care while allowing residents to enjoy autonomy and a sense of personhood. Every aspect of the “villages” is designed to increase or maintain the health of patients while promoting space and freedom for them to feel like they are still integral parts of society. Continuation of daily living patterns like cooking, dining in restaurants,

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<sup>183</sup> Joann Plockova, *As Cases Soar, ‘Dementia Villages’ Look Like the Future of Home Care*, N.Y. TIMES (July 3, 2023), <https://www.nytimes.com/2023/07/03/realestate/dementia-villages-senior-living.html>.

<sup>184</sup> *Inspiring Dutch Village for Those with Dementia*, OPERA BEDS (last visited Oct. 29, 2024), [https://operabeds.com/blogs/news/dutch-dementia-village?\\_its=JTdCJTlydmlkJTlyJTNBjTIyNGQyZTY0YmYtNTc1Zi00Yzg2LWE4ZTktOTVjZDliNzgxOTE1JTlyJTJDJTlyc3RhdGUIMjIIM0EIMjJybHR%2BMTY5NDY5MTA5NH5sYW5kfJfOTMxMjJfc2VvXzU3NzgyYzU1MzgwMTkzNWY4MjVhNjQ1NTJjYTc3OWEyJTlyJTJDJTlyc2l0ZUIkJTlyJTNBMTQxNDQIN0Q%3D](https://operabeds.com/blogs/news/dutch-dementia-village?_its=JTdCJTlydmlkJTlyJTNBjTIyNGQyZTY0YmYtNTc1Zi00Yzg2LWE4ZTktOTVjZDliNzgxOTE1JTlyJTJDJTlyc3RhdGUIMjIIM0EIMjJybHR%2BMTY5NDY5MTA5NH5sYW5kfJfOTMxMjJfc2VvXzU3NzgyYzU1MzgwMTkzNWY4MjVhNjQ1NTJjYTc3OWEyJTlyJTJDJTlyc2l0ZUIkJTlyJTNBMTQxNDQIN0Q%3D).

<sup>185</sup> *Id.*

<sup>186</sup> *Id.*

<sup>187</sup> See Plockova, *supra* note 183183.

<sup>188</sup> *Id.*

<sup>189</sup> OPERA BEDS, *supra* note 184.

<sup>190</sup> Plockova, *supra* note 183.

<sup>191</sup> *Id.*

<sup>192</sup> *Id.*

walking, interacting with others, gardening, and other “normal” activities provide access to a healthy balance of quality, affordable, autonomous care.<sup>193</sup> The patients remain valued as individuals in society while being provided for within a care community. Allowing corruption in the care of cognitively impaired individuals perpetuates the idea these individuals lack moral status and are unworthy of being treated as full human beings.<sup>194</sup> We owe protection to this vulnerable group and we have obligations as humans to care for them as they once cared for us.

## CONCLUSION

Let’s recall Margaret, our patient with Alzheimer’s disease from earlier in this article.<sup>195</sup> Margaret should have access to the same quality of care no matter her financial resources, familial support, or geographic location. Margaret should not have to suffer inadequate care because she does not come to the table with abundant resources. Margaret shouldn’t be further burdened by the disease that has claimed her mind, the disease she did not ask for. Margaret should never feel as though she is not valued and respected as a living human being. We must utilize effective policies and procedures to protect people like Margaret, who cannot help themselves.

We shouldn’t have to increase surveillance to ensure a lack of abuse. We shouldn’t have to drop in unannounced to detect maltreatment. We shouldn’t have to fight to remember this vulnerable population exists and is being harmed. The “shouldn’ts” are endless. Yet, in our non-ideal world, we *must* do these things. Older individuals living with Alzheimer’s disease often face tremendous barriers to accessing the high-level quality of care they require. Many struggle to finance residential care in a long-term care facility, such as a nursing home or a memory care unit. Even when resources allow one to finance a spot in a long-term care facility, many with Alzheimer’s disease and other related dementias are grossly abused, neglected, and abandoned. This is a morally corrupt system lacking virtue and failing to uphold the basic bioethical principles introduced by Beauchamp and Childress.<sup>196</sup>

Services do not have to be actively unjust to make them less than optimal

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<sup>193</sup> Emily Roberts, A Conversation About the Ethics of Past and Future Memory Care Models: Perspectives from the First Two European Dementia Villages, 60 J. HEALTH CARE ORG. PROVISION & FIN. (2023), at 3-4, <https://journals.sagepub.com/doi/full/10.1177/00469580221150565>.

<sup>194</sup> Beauchamp & Childress, *supra* note 8, at 75.

<sup>195</sup> See *supra* Part II.

<sup>196</sup> Beauchamp & Childress, *supra* note 8.

or likely to result in unjust impacts. In an ideal world, professional memory care in long-term care facilities would not be actively unjust. In an ideal world, regulations would restrain the power of dementia care workers, demand financial transparency in long-term care facilities, and deter harmful treatment. In an ideal world, professional care would not be the last resort for many people who have loved ones with Alzheimer's or other dementias. Age is inevitable. For most, cognitive and physical decline is inevitable. Policymakers must focus on protecting *all* human life, including those deemed "less valuable" due to age. This is not some utopian idea of a perfect world with no moral conflicts. This is a call for a system where a person's value is not measured by their net worth.

Healthcare should be about *care*, not the *business* of care. When professional care services in long-term facilities prove to be unjust and inadequate, we feel the bubbling development of a moral duty to provide informal care for those close to us with dementia. But informal dementia care should be the last choice. Policies should be tailored to ensure that lackluster care options are not the only options for persons with Alzheimer's and other forms of dementia. In our imperfect world, a diagnosis of Alzheimer's or other dementia is more than an incurable cognitive disability; it brings a litany of financial challenges, a continuous struggle for dignity, and a gradual fading from significance, all while losing defining traits and cherished memories.

*We* ought not to allow this vulnerable group to fade. *We* cannot continue to sweep this group under the rug. *We* shouldn't forget.