

# Mistreatment of People with Dementia

This research brief synthesizes the latest available information and research relating to the mistreatment of **people with dementia** (PWD). Vulnerabilities associated with dementia expose individuals to an increased risk of abuse and neglect. For PWD with chronic medical conditions and co-morbidities, the risk of harm may be compounded. Offenders are often family caregivers who lack the knowledge and tools to appropriately care for their loved one and manage the complexities and manifestations of the disease. Overwhelmed by the weight of responsibility, as well as the personal, social, financial, and health impacts, some caregivers, may mistreat loved ones.



Though caregiver resources and tools have been developed, and research has been conducted to understand the nexus between dementia and mistreatment, continuing efforts are needed to **empower and safeguard PWD and support caregiving families** to provide optimal and informed care.

## Key Takeaways

- Dementia is a risk factor for elder abuse, but more studies are needed to understand the context in which it occurs, as well as strategies for prevention
- Behavioral symptoms associated with dementia, rather than memory loss and cognitive decline, may trigger abusive behaviors by caregivers
- Detecting elder abuse in this population is challenging given PWD's cognitive impairment, communicative limitations, and reluctance to report family caregivers
- PWD, when able, should be involved in planning their care needs in order to provide care that respects the dignity and wishes of the older adult
- There is a critical need to develop evidence-based approaches to reduce or prevent abuse of PWD in the community and within facilities
- Protecting PWD from mistreatment is a multidisciplinary effort that includes strategies to support caregivers, enhance knowledge about dementia and elder abuse, and develop policies that promote high quality care that meets the unique needs of PWD



## Background

Dementia is an umbrella term for a broad range of specific medical conditions including loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life, activities, and independence.<sup>1</sup> Formally described as “major neurocognitive disorder,”<sup>2</sup> conditions grouped under this classification are caused by abnormal brain changes that trigger a decline in cognitive abilities, behaviors, and functioning.<sup>3</sup>

Alzheimer’s disease is the most common form of dementia, accounting for 60-80% of cases. Other types of dementia include vascular dementia, Parkinson’s disease, and dementia with Lewy bodies.<sup>4</sup>

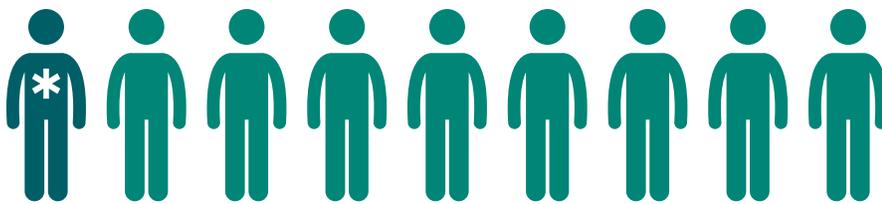
### Types of dementia:

Alzheimer’s disease (60-80%)

Vascular

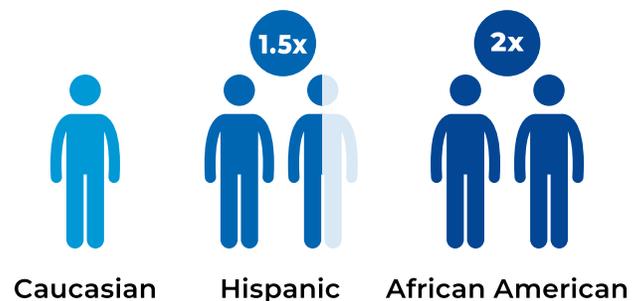
Parkinson’s disease

Lewy body



Nationwide, approximately **6.7 million (or 1 in 9)** people aged 65 and older live with Alzheimer’s disease and related dementias (ADRD).<sup>5</sup> Over seventy percent are age 75 or older. Women are nearly **two times more likely** to be affected than men.<sup>6,7</sup>

Older persons from diverse communities are at **a disproportionately higher risk** of developing dementia. African American elders are nearly two times more likely to have ADRD than Caucasian elders.<sup>8</sup> Hispanic older adults are about one and one-half times more likely to have ADRD than Caucasian elders.



Health conditions including heart disease and diabetes may account for these disparities, given their increased prevalence in African American and Hispanic communities. Social determinants of health such as lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination may also increase the risk of ADRD among these populations.<sup>9</sup>



**By 2060**, it is estimated that the number of people over the age of 65 with ADRD could grow to a projected **14 million nationwide**.<sup>10</sup>

## Dementia, Caregiving, and Elder Mistreatment

Dementia is a degenerative disease with significant physical, social, and economic consequences for both caregivers and care recipients. For older adults, progressive and irreversible decline results in more complex symptoms, behaviors, and care needs. As PWD are less able to independently undertake activities of daily living, they require increasing support and become more reliant on family/chosen family caregivers for assistance. The amount of time required for caregiving increases as dementia progresses.<sup>11</sup>



Caregivers of PWD report providing **27 hours more** care per month on average than caregivers of people without dementia.<sup>12</sup>

For many family/chosen family caregivers, the heightened care needs and growing responsibilities for a loved one with dementia can be challenging to navigate. Many caregivers lack the knowledge, skills, and tools to adequately manage the rising care needs of PWD. In addition, approximately 98% of PWD develop neuropsychiatric symptoms associated with the disease that may manifest as agitation, aggression, apathy, and depression. Mood and behavior changes associated with dementia are often more harmful to the caregiver-care recipient dyad than the patient's memory decline and decreased cognitive capability alone.<sup>13</sup>

**Neuropsychiatric symptoms 98% of PWD develop:**



**Agitation**



**Aggression**



**Apathy**



**Depression**

Escalating symptomology among PWD and the corresponding caregiver burden can result in physical, mental health, and financial impacts on caregivers. Distress among family caregivers is linked to increased rates of care recipient institutionalization and worsened behavioral and psychological symptoms in PWD.<sup>14</sup> Caregiver burden and burnout are also associated with elder mistreatment of PWD.<sup>15,16</sup> Rates of abuse (mistreatment and self-neglect) were higher among PWD than in their cognitively sound counterparts.<sup>17</sup> A Norwegian study of informal caregivers of PWD found that the risk of abuse was higher when the caregiver was a partner or spouse and if they had experienced aggression from the PWD.<sup>18</sup> Mistreatment can manifest in numerous ways including emotional, physical, and financial abuse, as well as neglect.





## Communication Neglect

One form of neglect observed with PWD is communication neglect, the deliberate or unintentional failure to communicate or relate to a PWD. Used as a punitive measure towards PWDs who are perceived as challenging (being uncooperative, inappropriate, or aggressive), communication neglect can isolate the older adult from critical socialization.<sup>19</sup>



## Sexual Abuse

In a study examining cases referred for prosecution, investigation, or forensic examination, alleged sexual offenders of PWD were most often known to the victims (family, formal caregivers, and fellow facility residents).<sup>20</sup> PWD exhibited behavioral cues of distress rather than verbally disclosing their victimization; many were easily confused, manipulated, and often beaten.<sup>21</sup> Though studies on abuse of PWD in long-term care facilities are limited, one study that addressed cases of reported sexual abuse found that nearly 60% of those assaulted involved PWD.<sup>22</sup>

## Prevalence Estimates

Numerous studies have identified dementia as a risk factor for elder abuse.<sup>23,24,25,26</sup>



It has been reported that nearly **one in two** PWD experience some form of mistreatment.<sup>27</sup>

The exact prevalence of mistreatment of PWD is difficult to quantify since most mistreatment is hidden and often under-reported.<sup>28</sup> Abuse is commonly committed against older adults by those closest to them. PWD may fail to report mistreatment due to being fearful of family caregivers upon whom they depend for essential care or they may be embarrassed to disclose family harm.

Alternatively, many PWD may be cognitively unable to report abuse or recognize that harm was inflicted. Estimates broadly range from 0.3% to 78.4% in the community, and from 8.3%–78.3% in institutional settings.<sup>29</sup> Within the community, self-neglect was also found to be significant and more frequent in PWD than among people without dementia.<sup>30,31</sup>

## Mitigating Mistreatment

In one study of family caregivers of PWD, researchers found that over a 21-day period, 74% identified at least one day when they engaged in abuse or neglect. The most commonly reported type was psychological aggression (64%) followed by neglect (50%) and physical aggression (12%). Through the reporting period, participants cited an average of 3.6 days that included abusive behavior and 2.7 days with neglect.<sup>32</sup> Caregiver stress related to a PWD's behavioral symptoms was associated with abuse and, more commonly, neglect.



If the caregiver had a meaningful, non-care-related, interaction with their care recipient twice in one day, they were **20% less likely** to engage in neglectful behaviors.

The risk of engaging in abusive behaviors varied from day-to-day and was mediated by the presence or absence of contextual factors such as the care needs of the PWD, the level of caregiver stress and coping skills, and the availability of social supports. The caregiver's participation in pleasant social activities with the care recipient was the only significant protective factor identified.<sup>33</sup>

## Types of Mistreatment

Generally, there are five types of elder mistreatment: physical, psychological/emotional, sexual, financial exploitation, and neglect. Research findings regarding the most prevalent forms of abuse among PWD vary. One recent study analyzing reported incidents of elder mistreatment to a national UK helpline found that PWD are more likely to be victims of financial exploitation.<sup>34</sup> These results are consistent with the rise in financial exploitation for older adults, generally and, in particular, those with dementia. An earlier review found greater prevalence of psychological abuse and physical harm among PWD as compared to other types of elder mistreatment, with estimates ranging from 27.9% to 62.3% for psychological and 3.5–23.1% for physical abuse in this population.<sup>35</sup> In a study of staffers in institutional care, two-thirds of staffers admitted abusing residents in the prior year, most often citing psychological abuse.<sup>36</sup>

PWD experience polyvictimization, or multiple forms of abuse simultaneously or successively.<sup>37,38</sup> In fact, a diagnosis of dementia has also been found to be a predictor of revictimization. Several factors were proposed to explain these findings, including caregiver burden, resistance to care, and aggressive behaviors of the PWD.<sup>39</sup> Another study that examined health conditions and elder mistreatment using Medicare beneficiary data found that with the category of neglect, conditions that lead to dependency, such as dementia, were the most commonly associated co-morbidities.<sup>40</sup>

### Types of Elder Mistreatment:



Physical



Emotional



Neglect



Financial



Sexual

## Stages of Abuse

The prevalence of specific types of mistreatment experienced by PWD may be associated with the stage and severity of the disease.<sup>41</sup> Anecdotally, clinicians have observed that certain types of mistreatment are associated with the stage of an ADRD disease.



**Early Stage ADRD:** Confusion and mild cognitive impairment is likely associated with a greater incidence of financial abuse



**Mid Stage ADRD:** Resistance to care and atypical behavioral disturbances are thought to be associated with physical abuse



**Late Stage ADRD:** Non-ambulatory and significant impairment are believed to be linked with increased neglect

## Factors Associated with Abuse

There are numerous factors associated with an increased risk of elder mistreatment, many that align with dementia symptomology and co-morbidities and the relational PWD-caregiver dyad.



### Victim Factors

- Mental health conditions
- Diminished cognitive ability
- Limited physical health<sup>42</sup>
- Lack of financial competency
- Psychological or behavioral symptoms such as agitation and aggression<sup>43</sup>
- Dependence on caregiver or others for care needs<sup>44</sup>
- Restricted social interactions<sup>45</sup>



### Perpetrator/Caregiver Factors

- Mental health conditions
- Alcohol misuse
- Social isolation
- Poor relationship with the PWD prior to the onset of dementia
- Caregiver burden and poor coping skills<sup>46</sup>
- In long-term care staff, a lower level of job satisfaction and a higher level of burnout rate<sup>47</sup>



### Community Risk Factors

- Absence of a dementia friendly community that promotes prevention of mistreatment<sup>48</sup>

## Barriers to Identification and Intervention

Barriers to the detection, reporting, and response to abuse of PWD exist on various ecosystemic levels:



### Victim-related Barriers

- Deficits in memory, communication, and judgment, may inhibit reporting<sup>49,50</sup>
- The fear of retaliation by caregivers may impede both reports of abuse and a timely and effective response<sup>51,52</sup>
- Lack of literature in native language



### Perpetrator/Caregiver Barriers

- Internalized feelings of shame, guilt, or denial<sup>53</sup> from negative thoughts about the PWD, inadequacies about the care provided, or institutional placement can trigger caregiver depression and the onset of abusive reactions.<sup>54</sup>
- Low “dementia literacy” and lack of literature in native language



### Professional Barriers

- Lack of awareness, knowledge, and training regarding dementia, and ethical dilemmas and concerns about the outcomes of the intervention<sup>55</sup>



### Organizational Barriers

- Unavailability or inaccessibility of services<sup>56</sup>
- Insufficient agency funding to support investigation<sup>57</sup>
- Inadequate multidisciplinary coordination to deliver needed resources<sup>58</sup>



### Socio-cultural Barriers

- Families may be unwilling to publicly disclose private matters<sup>59</sup>
- Cultural beliefs and stigma about the disease
- Marginalization and discrimination of PWD<sup>60</sup>

## Capacity and Abuse Reports

As noted earlier, ADRD is progressive and irreversible. PWD have varying degrees of capacity at each stage of the disease. Capacity is defined as the ability to do a specific task or make a specific decision and embraces both functional and decisional abilities. Capacity varies by task, time, and context. PWD may have the capacity to do one thing, but not another.

Regardless of the stage of disease, PWD, especially those in the early and middle stages of disease, are often able to communicate their choices, share their preferences and values, and report abuse.<sup>61</sup> Despite the challenges for many PWD, one study of older adult patients in emergency departments found that for more than half (59%) of patients with cognitive impairment, assessors were confident or absolutely confident in the patient's ability to report abuse.

Assessors expressed confidence in reports made by 11 of 12 patients with mild cognitive impairment and 7 of 11 patients with moderate to severe impairment.<sup>62</sup> For those with advanced disease, however, recognition and reporting of mistreatment may be more challenging.



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## Residents in Long-Term Care

Over half of nursing home residents live with ADRD.<sup>63</sup> All are dependent on staff for care. Many PWD have cognitive and functional limitations, co-morbidities, and behavioral indicia of ADRD. These challenges necessitate a greater level of care from direct care workers who may lack the knowledge, skill, and experience to navigate the demands and stresses of the job. This tension exposes PWD in facilities to a heightened risk of mistreatment.<sup>64</sup> Residents who exhibit dementia-related aggression are at even higher risk of mistreatment within nursing homes.<sup>65</sup> The institutional context lends itself to a decrease in empathy and respect for the care recipient's humanity, which can be a facilitator of abuse.<sup>66</sup> Examples of mistreatment in facilities include threatening residents who have dementia, avoiding those with challenging behaviors, and sexual abuse.<sup>67</sup>

There is limited research on elder abuse in nursing homes, but professionals working with PWD have reported high rates of abusive behavior. A systematic review revealed that overall abuse estimates, based on staff self-reports, indicate that 64.2% of staff admitted abusing residents in the past year.<sup>68</sup> In one survey, a quarter of relatives of care home residents with dementia reported physical abuse incidents.<sup>69</sup> Common causes and risk factors leading to abuse of PWD in these settings include poor training, adverse work conditions, inadequate screening for prior abuse of PWD, and apathy or bad attitudes of staff.<sup>70</sup> Researchers have suggested that documentation and careful attention to residents with dementia are crucial. An integrated effort, comprised of facility leadership, staff, physicians, and the community, is necessary to promote safety and prevent abuse.<sup>71</sup>

## Resident-to-Resident Aggression

While PWD are vulnerable to institutional abuse, in some cases they are aggressors towards fellow residents.<sup>72</sup> One study found that verbal aggression was the most frequently reported type of abuse (72%), followed by physical (66%) and sexual (18%) abuse.<sup>73</sup>

Aggressive behaviors by PWD may be associated with neuro-psychiatric conditions that can accompany dementia.<sup>74</sup>

They may also be impacted by the needs of the PWD, the specific circumstances, and environmental factors.<sup>75</sup>

Person-centered care has been proposed to de-escalate the aggression without undermining the dignity of the resident. As opposed to medication, this approach may ensure that unmet needs are addressed. This aligns with current recommendations to reduce the use of antipsychotic medication in facilities.<sup>76</sup>



**Person-centered care** has been proposed to de-escalate aggression while supporting the dignity of the resident.

## Most frequently reported types of abuse:



72% Verbal



66% Physical



18% Sexual

## Dementia Stereotypes and Ageism

Ageist stereotypes of older adults often draw upon behaviors and concepts associated with symptoms of dementia, such as perceptions that older adults are dependent and burdensome. Viewing PWD through a monolithic lens is insupportable and stems from a lack of awareness and understanding about the disease. Stigmatization can lead to negative attitudes towards PWD, exposing them to misunderstanding, embarrassment, isolation, and potentially mistreatment.<sup>77</sup> Notably, caregivers who experience emotional, physical, and financial vulnerabilities may be more likely to display ageist biases, which can adversely impact those under their care.<sup>78</sup>

At the other end of the spectrum, a meta-analysis found that “personhood,” or the extent to which others value, support and establish meaningful relationships with PWD, is enhanced through personal interactions with family, friends, other people with dementia and professional caregivers as well as through opportunities for ongoing engagement in social activities.<sup>79</sup> Individual empowerment and autonomy should be supported when possible to enhance PWD quality of life.



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## Interventions

The following are suggested intervention strategies in the areas of practice, research, education, and policy.

### Practice

- Provide education, family counseling, and other services such as respite and support groups to mitigate the burden of care and prevent abuse,<sup>80,81,82</sup>
- Implement intervention strategies that consider PWD vulnerability, levels of dependency on the caregiver, and resources to supplement existing support<sup>83</sup>
- Assess depressive symptoms in caregivers<sup>84</sup>
- Train health providers to screen for the risk and presence of abuse in PWD<sup>85</sup>
- Develop or adapt screening and assessment tools in different cultural contexts<sup>86</sup>
- Educate clinicians about the potential risk of abuse associated with different stages of dementia<sup>87,88</sup>
- Promote high quality care in facilities that involves continuous monitoring by leadership and staff, to ensure the PWD's living arrangements are safe and modified when necessary<sup>89</sup>
- Increase collaboration between Adult Protective Services and groups serving PWD and family/chosen family caregivers, through organizations such as Alzheimer's Association<sup>90</sup>
- Adopt interventions to reduce staff burnout and depersonalization, introduce true person-centered care by encouraging staff to explore residents' personal histories, current and past interests, and build pleasant interactions into care, as well as reducing objectification of PWD<sup>91</sup>

### Research

- Given the factors that may portend abuse among PWD, study personality changes in PWD, increase of caregiver burden and isolation, and social stigma and social exclusion associated with dementia<sup>92</sup>
- Employ detailed assessments of day-to-day risk and protective factors of caregiver abuse, including changes in stressors, and known family violence risk factors.<sup>93</sup>
- Consider variables on the micro and macro level (not just the caregiver relationship)<sup>94</sup>
- Conduct research with underserved communities to inform a more representative evidence base<sup>95</sup>
- Explore culturally specific issues related to the definitions and perceptions of mistreatment of PWD<sup>96</sup>
- Replicate tested caregiver interventions in the community in order to affirm their effectiveness, and create a registry of caregiver interventions that are easily accessible to researchers and the public<sup>97</sup>



## Education

- Implement educational programs focusing on PWD's vulnerability to abuse<sup>98</sup>
- Distribute culturally appropriate information and community education materials for caregivers on ADRD and elder mistreatment<sup>99</sup>
- Educate long-term care professionals about the risk of abuse, prevention, and detection in PWD<sup>100</sup>
- Educate health professionals in the concept of caregiver guilt and the potential risks it poses for the mental health of the caregiver and safety of the PWD<sup>101</sup>
- Incorporate psychotherapeutic elements into educational interventions for dementia caregivers<sup>102</sup>



## Policy

- Adopt policies that promote education regarding the risks associated with dementia and exposure of abuse and neglect<sup>103</sup>
- Promote better health policies to ensure the quality of life of PWD (e.g. policies that promote community-based living, community engagement to decrease isolation, and support for caregivers)<sup>104</sup>

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