



Preventing Abuse by Family Caregivers

The intersection of caregiving and elder abuse is rarely discussed yet deserves attention. Supporting caregivers safeguards and supports the older adults in their care.

Who are Caregivers?

Informal caregivers can be relatives, spouses, partners, friends, or neighbors who have significant relationships with, and who provide a broad range of assistance to, older adults or adults with disabilities. Although most caregivers provide care for free, some are reimbursed through the In Home Support Services program. This brief refers to informal caregivers, as opposed to caregivers who work for agencies.



The Importance of Caregivers

California’s long-term services and support system for older adults and adults with disabilities relies, in large part, on unpaid family members and friends. Each year, over 4 to 5 million family caregivers in California provide \$47 billion in “free” care.(6) This silent army contributes over 80% of the care provided to those in need. If this care was not provided, many of these older adults and adults with disabilities would be institutionalized sooner, placing a burden and cost on our nation’s long-term care facilities. Nationally, the estimated costs for these unpaid services are twice what the government spends annually on professional home care and nursing home care combined.(6)

Although most caregivers willingly undertake the role and intend to provide excellent care, the nearly 24/7 responsibility for caregiving chores, including increasingly complex medical interventions and physical assistance, takes its toll:

- More than 1 million California caregivers report moderate or serious distress levels.(7)
- The one-third of California caregivers who live with their care recipients spend an average of 36 hours a week providing care.(7)
- 40% to 70% of family caregivers have clinically significant symptoms of depression with about a quarter to half meeting the diagnostic criteria for major depression.(9)
- 67.1% of caregivers hold down full or part-time jobs.(2)
- 70% of working caregivers suffer work-related difficulties due to their caregiving role.(2)

Society too shares the cost in lost productivity. It is estimated that U.S. businesses, may lose between \$17.1 and \$33 billion each year due to absenteeism, reduction of hours, replacing employees, and work-day adjustments needed by overwhelmed caregivers.(2)

The Intersection of Elder Abuse and Caregiving

Despite their enormous contributions, caregivers receive little support or education to prepare them for the daunting task of caring for older adults with cognitive impairments (e.g., dementia), psychological issues (e.g., depression, paranoia) and multiple chronic conditions (e.g., diabetes, hypertension, arthritis). Less than 20% of caregivers report having received training on how to be a caregiver. Caregivers often feel as if their needs are invisible to physicians, health systems, and policy makers.

Is it any wonder then, that two studies show that as many as 47% of family caregivers of people with dementia are more inclined to engage in abusive behavior? (3),(8)

One in ten older Americans are believed to experience abuse each year in the United States, according to the National Institute of Justice.(1) But as few as one in 23 cases are ever reported.(4) Both abuse victims and caregivers are suffering in silence.

Abuse is preventable, but it requires research, education, advocacy and public awareness. One approach is to value our caregivers and give them the support and information needed to ease their burden and help them with their responsibilities.

It is clear that by devaluing caregivers we are putting our older and disabled adults at risk.


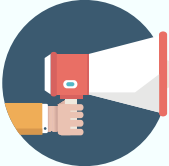


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Taking Action to Prevent Abuse by Caregivers

The California Elder Justice Coalition (CEJC) believes that California can lead the way in supporting caregivers. CEJC's *Blueprint for Improving California's Response to Elder Abuse, Neglect, and Exploitation* calls for the following:

- 1) Promote the use of caregiver assessments to identify and respond to high risk situations. Caregiver assessment refers to a systematic process of gathering information about caregiving situations to identify caregivers' strengths, problems, and needs. Assessments should ask questions that yield information related to the warning signs of abuse and neglect. California could require that Title III-E Family Caregiver Support Programs develop a universal performance-based assessment tool for counties to ensure uniformity.
- 2) Design and mount a public awareness campaign to help caregivers realize that resources are available, identify as caregivers (many caregivers do not identify with this label), and help them identify the "tipping points" (warning signs for abuse, neglect, or exploitation).
- 3) Increase funding for California Caregiver Resource Centers and Caregiver Programs sponsored by the Area Agencies on Aging to provide education and support to reduce symptoms of anxiety, burden, depression and resentment, all of which are warning signs of abuse or neglect.
- 4) Ensure that professionals who work with older adults (e.g., physicians, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it. Conversely, professionals in the elder justice system (e.g., Adult Protective Services, Long-term Care Ombudsman, law enforcement) need education about programs available to support caregivers.
- 5) Hold abusive caregivers accountable. In some instances, caregivers provide care for the wrong reasons. Some are incapable of providing good care and others are pressured into providing care. In some instances, predatory individuals use their role to exploit those in their care. Care receivers may need help to screen and monitor caregivers, and recourse if abuse occurs.

Conclusion

Older Americans are the fastest growing segment of the population, and California is home to the largest number of older adults in our country. Let's celebrate the spirit of caregivers whose giving of themselves without expectation of remuneration or recognition helps thousands of elders stay in the community. Let us support them and through them support older Californians to live out their golden years with dignity and respect in the Golden State.

For more information, please contact the California Elder Justice Coalition at info@elderjusticecal.org. Or visit our website at: <http://elderjusticecal.org>.

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