

# Family Caregivers and Trauma

## Who is a Family Caregiver?

A family caregiver is a family member, partner, or friend who provides a broad range of assistance to an older adult or adult with a chronic, disabling, or serious health condition. Family caregivers are not professionally employed to care for their loved one, may or may not have prior experience in caregiving, and can live with or separately from those they care for.<sup>1</sup>

## What does a Family Caregiver do?

Family caregivers provide their loved ones with a wide range of support from dressing and bathing, to emotional companionship, administering medication, or carrying out medical or nursing tasks. Additionally, family caregivers are often employed in the workforce and care for other dependents. Family caregivers,<sup>2</sup>

- Help with daily activities including errands
- Provide emotional and social support
- Perform complex medical and nursing tasks
- Coordinating medical treatment and care

### 95%

of older adults receive some help with daily activities from their family or close friends<sup>3</sup>

### 66%

of older adults rely solely on family caregivers<sup>4</sup>

### 48%

of older adults have difficulty carrying out daily living activities without assistance<sup>5</sup>

## 41 Million

individuals in the United States are family caregivers, more than the population of California<sup>6,7</sup>

## 34 Billion

hours of care are provided by family caregivers in the United States annually<sup>8</sup>

## \$470 Billion

family caregivers provide annual care valued at \$470 billion<sup>9</sup>



The economic value of Family Caregivers compares to the following sectors of annual spending in the United States:<sup>10</sup>

### \$366B

Out-of-Pocket Health Care Spending

### \$470B

Family Caregiver Value

### \$366B

Overall Long-Term Care Spending

### \$145B

Medicaid Long-Term Care Spending

### \$438B

Agriculture/Forestry and Mining Sector

### \$460B

Education and Arts/Entertainment Sector



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# Family Caregivers and Trauma

## Family Caregiver Burden

While caregiving for a family member or friend can be a rewarding experience, it is also one that can take a financial, emotional, and physical toll. <sup>11, 12</sup> Family caregivers can experience,



Increased emotional hardships on individual or family relationships



Increased financial burden of providing care and/or forgoing paid work



Increased exhaustion from the physical demands of caregiving



Increased risk for chronic loneliness and social isolation



Increased levels of stress and anxiety



Increased levels of depression, which can persist after nursing home placement



Decreased rate of self-care and health maintenance behaviors



Worsening physical health

**72%** of caregivers report that they do not go to the doctor as often as they should <sup>13</sup>

**63%** of caregivers report worsening eating habits as a result of caregiving responsibilities <sup>14</sup>

**58%** of caregivers report worsening exercising habits as a result of caregiving responsibilities <sup>15</sup>

**55%** of caregivers missed doctor appointments <sup>16</sup>

**45%** of caregivers report chronic conditions at nearly twice the rate of non-caregivers <sup>17</sup>

**11%** of caregivers report that caregiving has caused their physical health to get worse <sup>18</sup>

**#1** Declining health among family caregivers is the leading cause of the institutionalization of their loved ones <sup>19</sup>

## Caregiving Can Be Rewarding

Many family caregivers find satisfaction in providing for their loved one's care. Family caregivers report learning new skills, developing a new appreciation for life, feeling needed, and forming stronger relationship with their loved one. <sup>20, 21</sup>



# Family Caregivers and Trauma

## Older Adults with Alzheimer's and other Dementias

Individuals with dementia suffer from progressive cognitive deterioration resulting in changing behaviors and needs. Thus, providing care for older adults with Alzheimer's and other dementias is very complex and challenging, placing additional stress and burden on family caregivers.<sup>22</sup>

**16 Million**

family caregivers in the United States provide care to those with Alzheimer's and other dementias.<sup>23</sup>

**80%**

of older adults with Alzheimer's and other dementias receive help with daily personal care activities (bathing, dressing, grooming, or eating), compared to 20% of adults without dementias who need similar support.<sup>24</sup>

## Employment Burden

Caring for older adults with Alzheimer's and other dementias is a significant burden on the professional employment of family caregivers. As a result, **more than 1 in 6 family caregivers of those with Alzheimer's and other dementias have to quit working to become a caregiver or because caregiving duties become too burdensome.** For family caregivers of those with Alzheimer's and other dementias who remain at work, many have to adjust their work schedule to accommodate caregiving responsibilities. Some family caregivers report being penalized at work for taking time off to care for loved ones with Alzheimer's or other dementias.<sup>25</sup>

**57%** had to go in late, leave early, or take time off of work<sup>26</sup>

**18%** had to reduce employment from full-time to part-time<sup>27</sup>

**16%** had to take a leave of absence from their work<sup>28</sup>

**8%** had to turn down a promotion at work<sup>29</sup>

## Health Burden

Providing care for individuals with dementia can be more stressful and physically demanding than caring for a physically impaired older adults.<sup>30, 31</sup> Of family caregivers of those with Alzheimer's and dementias, many report worsening physical and mental health.

**2X** Family caregivers for individuals with Alzheimer's and other dementias are twice as likely to suffer from depression than other family caregivers<sup>32</sup>

**6X** Spousal caregivers for individuals with Alzheimer's or other dementias are six times more likely to develop dementia compared to non-caregivers<sup>33</sup>

**75%** are somewhat or very concerned about maintaining their own health<sup>34</sup>

**60%** experience high or very high emotional stress<sup>35</sup>

**33%** report worsening health due to caregiving responsibilities<sup>36</sup>

**63%** Family caregivers for individuals with Alzheimer's or other dementias experience a 63% increased risk of death over four years compared to non-caregivers.<sup>39</sup>

## Family Caregiver Mortality

The burden of caring for a person with dementia is significant and can affect a family caregiver's mortality.<sup>37</sup> A study looking at spousal caregivers of hospitalized individuals found that if the hospitalized individual had dementia, the spousal caregiver was more likely to die within a year than if the care recipient did not have dementia, even after accounting for the age of the caregiver.<sup>38</sup>



# Family Caregivers and Trauma

## Caregiving for Older Adults with a History of Trauma

Providing care for a family member or friend with a history of trauma can increase the complexity associated with their care.



### Family caregivers may not know how to avoid trauma triggers

Smell, touch, sound, and caregiving situations can trigger memories or emotions from previous trauma.



### Family caregivers may not know how to respond to trauma symptoms

Family caregivers may not know how to soothe the distress, anger, confusion, or panic as their loved one experiences flashbacks, nightmares, or intrusive thoughts associated with a history of trauma.



### Family caregivers may not know how to respond to trauma-related behaviors

Older adults with a history of trauma may display behaviors such as hoarding or social isolation. Some older adults experiencing cognitive decline may focus on retelling traumatic events. These behaviors may complicate caregiving tasks.



### Trauma can place a strain on caregiving relationships

Individuals with a history of trauma may have difficulty trusting others, developing intimacy, and building a relationship with their caregivers.



### Individuals with a history of trauma may avoid professional medical care

Trauma can lead to a distrust of health care providers and a reluctance to use healthcare systems for fear of being misunderstood, blamed, or re-traumatized. This shifts a greater burden of care onto family caregivers.

## Caregiving of Veterans

Many wounded, injured, or disabled veterans rely on family caregivers for daily care and support. While this support is necessary for veterans to age in place, caregiving for older adults with a history of trauma can be challenging and comes with increased burdens. Family caregivers of military veterans consistently experience worse health than non-caregivers, report more workplace problems than other family caregivers, and are at increased risk for social isolation and depression than other caregivers.<sup>40, 41, 42</sup>



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## Sources

1. Reinhard, S. Friss Feinberg, L., Houser, A., Choula, R., & Evans, M. (2019). Valuing the Invaluable, 2019 Update: Charting a Path Forward. AARP Public Policy Institute. <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>
2. Ibid
3. Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older Americans. *The Milbank quarterly*, 92(3), 509–541. <https://doi.org/10.1111/1468-0009.12076>
4. Ibid
5. Ibid
6. United States Census Bureau (2019). State Population Totals and Components of Change: 2010-2019. [https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-total.html#par\\_textimage\\_1574439295](https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-total.html#par_textimage_1574439295)
7. Reinhard, S. Friss Feinberg, L., Houser, A., Choula, R., & Evans, M. (2019). Valuing the Invaluable, 2019 Update: Charting a Path Forward. AARP Public Policy Institute. <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>
8. Ibid
9. Ibid
10. Ibid
11. Ibid
12. Family Caregiver Alliance. Caregiver Health. National Center on Caregiving [Fact Sheet] <https://www.caregiver.org/-caregiver-health>
13. National Alliance for Caregiving & Evercare. (2006). Evercare® Study of Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One. <https://www.caregiving.org/wp-content/uploads/2020/05/Caregivers-in-Decline-Study-FINAL-lowres.pdf>
14. Ibid
15. Ibid
16. Ibid
17. Ho, A., Collins, S. R., Davis, K., & Doty, M. M. (2005). A look at working-age caregivers' roles, health concerns, and need for support. Issue brief (Commonwealth Fund), (854), 1-12.
18. Center on Aging Society. (2005). How Do Family Caregivers Fare? A Closer Look at Their Experiences. Georgetown University (Data Profile, Number 3).
19. Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American journal of public health*, 97(2), 224–228. <https://doi.org/10.2105/AJPH.2004.059337>
20. Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving. *Research on Aging*, 26(4), 429–453. <https://doi.org/10.1177/0164027504264493>
21. Hilgeman, M. M., Allen, R. S., DeCoster, J., & Burgio, L. D. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and aging*, 22(2), 361–371. <https://doi.org/10.1037/0882-7974.22.2.361>
22. Tremont G. (2011). Family caregiving in dementia. *Medicine and health, Rhode Island*, 94(2), 36–38. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3487163/>
23. Alzheimer's Association (2020). Alzheimer's Disease Caregivers [Fact Sheet]. [https://act.alz.org/site/DocServer/caregivers\\_fact\\_sheet.pdf?docID=3022](https://act.alz.org/site/DocServer/caregivers_fact_sheet.pdf?docID=3022)

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## Sources

24. Alzheimer's Association (2020). Alzheimer's Disease Caregivers [Fact Sheet]. [https://act.alz.org/site/DocServer/caregivers\\_fact\\_sheet.pdf?docID=3022](https://act.alz.org/site/DocServer/caregivers_fact_sheet.pdf?docID=3022)
25. Ibid
26. Ibid
27. Ibid
28. Ibid
29. Ibid
30. Tremont G. (2011). Family caregiving in dementia. *Medicine and health, Rhode Island*, 94(2), 36–38. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3487163/>
31. Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and aging*, 18(2), 250–267. <https://doi.org/10.1037/0882-7974.18.2.250>
32. Family Caregiver Alliance. Depression and Caregiving. National Center on Caregiving [Fact Sheet] <https://www.caregiver.org/depression-and-caregiving>
33. Norton, M. C., Smith, K. R., Østbye, T., Tschanz, J. T., Corcoran, C., Schwartz, S., Piercy, K. W., Rabins, P. V., Steffens, D. C., Skoog, I., Breitner, J. C., Welsh-Bohmer, K. A., & Cache County Investigators (2010). Greater risk of dementia when spouse has dementia? The Cache County study. *Journal of the American Geriatrics Society*, 58(5), 895–900. <https://doi.org/10.1111/j.1532-5415.2010.02806.x>
34. Alzheimer's Association (2020). Alzheimer's Disease Caregivers [Fact Sheet]. [https://act.alz.org/site/DocServer/caregivers\\_fact\\_sheet.pdf?docID=3022](https://act.alz.org/site/DocServer/caregivers_fact_sheet.pdf?docID=3022)
35. Ibid
36. Ibid
37. Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a spouse. *The New England journal of medicine*, 354(7), 719–730. <https://doi.org/10.1056/NEJMsa050196>
38. Schulz R., & Beach, S.R. (1999). Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *JAMA* 282(23):2215–2219. <https://doi.org/10.1001/jama.282.23.2215>
39. Tremont G. (2011). Family caregiving in dementia. *Medicine and health, Rhode Island*, 94(2), 36–38. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3487163/>
40. Ramchand, R., Tanielian, T., Fisher, M.P., Vaughan, C.A., Trail, T.E., Batka, C., Voorhies, P., Robbins, M.W., Robinson, E., & Ghosh-Dastidar, B., (2020) Hidden Heroes: America's Military Caregivers. RAND Corporation, RR-499-TEDF. [https://www.rand.org/pubs/research\\_reports/RR499.html](https://www.rand.org/pubs/research_reports/RR499.html)
41. Mileski, M., Scott Kruse, C., Brooks, M., Haynes, C., Collingwood, Y., & Rodriguez, R. (2017). Factors Concerning Veterans With Dementia, Their Caregivers, and Coordination of Care: A Systematic Literature Review. *Military medicine*, 182(11), e1904–e1911. <https://doi.org/10.7205/MILMED-D-16-00396>
42. Pinciotti, C.M., Bass, D.M., McCarthy, C.A., Judge, K.S., Wilson, N.L., Morgan, R.O., Snow, A.L., & Kunik, M.E., (2017). Negative Consequences of Family Caregiving for Veterans With PTSD and Dementia. *The Journal of Nervous and Mental Disease* 205(2) 106-111 <https://doi.org/10.1097/NMD.0000000000000560>

