

VA formally defines the term caregiver as being an individual who provides personal care services to a Veteran. Family Caregiver, a term inclusive of both primary and secondary caregivers, is defined as an individual who is at least 18 years of age and who: (a) is the Veteran's spouse, son, daughter, parent, stepfamily member, or extended family member, or; (b) lives with the Veteran full time or will do so if designated as a family caregiver but is not a member of the family of the Veteran. A General Caregiver is defined as an individual who: (1) is not a Primary or Secondary Family Caregiver; and (2) provides personal care services to a covered Veteran, even if the individual does not reside with the Veteran.¹

Issue

An estimated 47.9 million Americans reported being a caregiver – an adult family member or other adult who lives with and provides personal care services for another adult - for an adult older than 18 years of age in 2019, or nearly 1 in 5 adults.² Of those, 14% reported being the caregiver for a Veteran.¹ Caregivers of Veterans report high levels of caregiving intensity (the average caregiver provided care most of the day for every day of the week), as well as high levels of financial strain, loneliness, feelings of burden, and depressive symptoms.³ The relationship between caregiving, suicidal behavior, and suicide is unclear: while some studies have found a link between caregiver status and suicidal ideation,⁴⁵ others have found no association between caregiving and either suicidal ideation⁶ or risk of death by suicide.⁵ Clinicians can support caregivers by showing a supportive attitude, involving caregivers as a part of the care team, and connecting caregivers with support groups, caregiver support services, and mental health care.⁵

Key Findings

Caregiver Status and Suicide Risk

- One large study of caregivers and volunteers in Northern Ireland evaluated the differences in mental health and suicide risk between caregivers and those engaged in other prosocial activities.⁶ The researcher found that while caregivers reported worse mental health than non-caregivers, both caregivers and volunteers were found to have a reduced risk for death by suicide.⁶
- Few studies directly compare suicidal ideation among caregivers and non-caregivers, and those studies have reported contradictory results. While one study reported that caregivers were twice as likely as noncaregivers to report thinking about suicide,⁴ another found no difference in the rate of suicidal thoughts between caregivers and non-caregivers.⁶
- Suicide risk among caregivers may be related to the specific circumstances of caregiving, rather than to caregiving status. A study evaluating the relationship between measures of physical, social, and emotional well-being and suicidal ideation among a sample of caregivers of Veterans or Service members identified three groups of caregivers defined by clusters of mental health, physical health, and caregiving characteristics: highdistress, medium-distress, and low-distress. Caregivers with the high-distress group were 27.64 times more likely to report prior suicidal ideation than those with the low-distress group, and caregivers with the mediumdistress group were 5.40 times more likely to report prior suicide ideation. Caregivers in the high- and mediumdistress group were more likely to care for Veterans with depression, PTSD, and suicidal ideation; caregivers in the low-distress group were more likely to care for a physical health condition.8
- Several studies have examined risk factors associated with suicidal ideation among caregivers. Risk factors



that were found to be significant included being unemployed,^{5,10} filling the role of primary caregiver,¹¹ living without a partner,^{5,9} lacking support from a cocaregiver,¹⁰ experiencing low levels of social support,⁵ depression,^{3,5,9,10} an anxiety disorder,^{5,9,10} and having impaired emotional or physical functioning,⁵ and decreases in reason for living.³

 Being unemployed and having financial difficulties were associated with suicide attempts among cancer patient caregivers with anxiety and depression, respectively.⁹

Impact on Caregivers

- Caregivers may experience differing levels of burden according to the illness experienced by the recipient of care. A meta-analysis found that the condition associated with the highest scores for caregiver burden was dementia/cognitive impairment, followed by mental health conditions, Alzheimer's disease, and physical disabilities.¹² Caring for an older person or other dependent with no identified illness was associated with the lowest scores of caregiver burden.¹¹
- Levels of caregiver distress and burden may also vary among those caring for someone with a mental health condition according to the behavioral and psychological symptoms experienced by those receiving care. A systematic review found that depressive behaviors, agitation or aggression, and apathy were reported as being the most distressing behaviors for caregivers, though the pooled data for studies which could be directly compared found that aberrant motor behavior and delusions were the symptoms most strongly correlated with distress.¹³ Delusions, agitation, disinhibition, and changes in appetite or eating habits were associated with increased caregiver burden.¹²
- Caregivers in the US general population report lower scores in measures indicating good mental and physical health than non-caregivers, and are more likely to have a diagnosis of insomnia, generalized anxiety disorder, and depression than noncaregivers.¹⁴
- Caregivers also have a higher prevalence of smoking and daily alcohol use compared to non-caregivers,

as well as work impacts including increased levels of absenteeism and presenteeism at work.¹³

Caregivers of Veterans

- Among Veterans, the conditions requiring a caregiver that were most frequently reported were depression, physical injury or illness, anxiety, posttraumatic stress disorder (PTSD), Alzheimer's disease or dementia, and heart problems.²
- In addition to reporting high levels of caregiving intensity, financial strain, loneliness, feelings of burden, and depressive symptoms, caring for a Veteran may have an impact on employment status. Prior to becoming a caregiver, 59.3% of those giving care to Veterans reported having full time employment, while after becoming a caregiver only 12.1% reported working full time.²
- Caregivers of Veterans with a traumatic brain injury (TBI) reported high levels of caregiver burden, as well as low scores on measures of good mental and physical health; moreover, lower scores for good mental and physical health were associated with higher caregiver burden.¹⁵
- Another study of Veterans with TBI found that lower levels of Veteran functioning and higher intensity of care required were associated with higher levels of caregiver burden.¹⁶ Higher levels of caregiver burden was, in turn, associated with lower levels of caregiver mental health.¹⁵ Moreover, higher scores on family functioning and the availability of social resources, such as social support or help with caregiving, were found to have a moderating effect on the associations between Veteran functioning, caregiving intensity, and burden; that is, the availability of family or social resources may reduce the negative effect of caregiving.¹⁵
- The perception of stigma toward caregivers and toward care recipients was associated with several negative outcomes among caregivers of Veterans with TBI.
 The perception by caregivers of being discriminated against and the perception of stigma associated with caregiving were associated with increased personal strain, depression, anxiety, and social isolation; the perception of discrimination against care recipients was associated with personal strain and social isolation among caregivers.¹⁷
- Caregivers of Veterans with polytrauma or injuries to multiple body parts or organ systems - who received



training in navigating VHA health systems reported lower levels of depression and caregiver burden compared to those who had not.¹⁸ Caregivers who had received education on the subject of supporting their Veteran family member's emotions also reported lower levels of anxiety, depression, and caregiver burden.¹⁷ Caregivers who had received either type of training reported higher levels of self-esteem than those who had not.¹⁷

 Caregivers of Veterans with PTSD experienced greater burden and higher levels of depression, anxiety, hostility, and obsessive-compulsive symptoms than the partners of Veterans without PTSD.¹⁹ Moreover, caregivers of Veterans with both PTSD and dementia were at greater risk of negative consequences such depression, worse perceived physical wellbeing, and greater levels of emotional strain.²⁰

Implications

Caregivers of Veterans experience high levels of caregiver burden, financial strain, loneliness, and depression. Caregivers in the general population report support needs in seven domains: information, emotional support, adequate wellbeing of those cared for, a supportive attitude from formal care providers, carer involvement in treatment, adequate wellbeing of the self, and practical help in performing the caregiver role. This suggests that, in addition to the beneficial role of training and formal support for Veteran caregivers, clinicians can help by providing informal support and involving caregivers in treatment planning as part of the team.

Ways You Can Help

- Welcome Veterans' caregivers as part of the treatment team and involve them in treatment planning. The Campaign for Inclusive Care is a partnership between VA and the Elizabeth Dole Foundation to furnish healthcare providers with the tools and training necessary to integrate caregivers into a Veteran's care team. More information can be found at https://campaignforinclusivecare.elizabethdolefoundation.org/.
- Consider referring caregivers of Veterans to the Program of General Caregiver Support Services (PGCSS), which offers coaching, skills training, group and individual support services, peer support mentoring and referrals to available resources within and outside of VA, to caregivers of Veterans from all service eras, with or without a service-connected condition. No formal application is required to enroll; to get started, caregivers of Veterans can contact the VA Caregiver Support Line (https://www.caregiver.va.gov/help_landing.asp) or can reach out directly to their local Caregiver Support Program Team. More information on the PGCSS can be found at https://www.caregiver.va.gov/Care_Caregivers.asp.
- Encourage caregivers and loved ones to explore VA's resources for family members and friends to learn more about
 different kinds of mental health challenges, how they are treated and how loved ones can help while learning tools to
 keep strong themselves. A list of resources can be found at https://www.mentalhealth.va.gov/families/index.asp.
- Consider referring the caregivers of Veterans who sustained or aggravated a serious injury or illness on or before May 7, 1975 or on or after September 11, 2001 to the Program of Comprehensive Assistance for Family Caregivers. More information on eligibility and how to enroll can be found at https://www.caregiver.va.gov/support/support_benefits.asp.
- Consider referring caregivers to the Resources for Enhancing All Caregivers Health (REACH) VA Program. REACH VA provides training and assistance with a variety of caregiving challenges, such as self-care, problem solving, and managing mood and stress. More information is available at https://www.caregiver.va.gov/REACH VA Program.asp.
- VA also provides resources for caregivers caring for people with dementia, including helping with daily life, learning new ways to communicate, and seeking support in a network of other caregivers. More information is available at https://www.veteranshealthlibrary.va.gov/Search/142,41448_VA and https://www.va.gov/GERIATRICS/pages/Alzheimers_and_Dementia_Care.asp



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