

Caregivers of Veterans – Serving on the Homefront

*Report of Study Findings
November, 2010*



Conducted by



Funded by



National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

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Introduction

Previous caregiver studies, including the 2009 *Caregiving in the U.S.*, revealed much about family caregiving nationwide—the demographics of both caregivers and care recipients and the impact of caregiving on the caregivers' finances, work life, health, and even their retirement. These studies have provided input to the development of the National Family Caregiver Support Program, corporate eldercare programs, and the Vice President's Middle Class Initiative.

Caregiving in the U.S. showed that 11% of all caregivers of adults have served in the armed forces, and 17% of their care recipients are veterans. With increased interest around caregivers of veterans in the Secretary of Veterans Affairs' strategic plan (2009) and the recently passed Caregivers and Veterans Omnibus Health Services Act of 2010, it became clear how valuable it would be to have a more in-depth qualitative and quantitative portrait of this special set of caregivers.

In conducting this study, the National Alliance for Caregiving and its funder, United Health Foundation, have led a first-of-its kind effort to assess the needs of caregivers of veterans from combat eras dating from World War II to the wars in Iraq and Afghanistan. While some of the challenges they face are shared by family caregivers in general, others are unique. The distinct nature of the veterans' illnesses and injuries drives different caregiving needs, and the array of governmental and community resources that serve veterans and their caregivers also distinguish their situations from those of other caregivers. As one striking example, some of the newly injured are in their twenties, with caregivers who may be parents entering their 50s and 60s and facing decades in this role.

In addition to identifying their challenges, the study was designed to understand how providing care affects caregivers' lives, what organizations and information sources have been helpful to them, and what programs and services would support and assist them. The study did not delve into issues relating to financial benefits provided to veterans.

The study combines qualitative results from a series of focus groups and in-depth telephone interviews with quantitative data from an online survey. Together, the three-part study provides information for policymakers, the Department of Veterans Affairs (VA), community agencies, non-profit organizations, and business and industry to better target programs to the needs of this special group of caregivers who are caring for those who have sacrificed so much for our country.

Methodology

This report is based primarily on a quantitative online survey with 462 self-identified family caregivers, age 18 or older, who provide care to a veteran whose injury, illness, or condition is related to military service.

The specific questions used to screen respondents are:

Are you a family caregiver of someone who served in the military? By this, we mean any unpaid relative or friend who helps care for the Veteran who needs assistance with everyday activities.

The unpaid care may include help with tasks such as personal care, bathing, dressing, feeding, giving medicines or treatments, help with memory tasks for someone with brain injury or Post Traumatic Stress Disorder (PTSD), transportation to doctors' appointments, or arranging for services, etc. You do not need to live with the Veteran.

Please think about the condition for which the Veteran needs your assistance. Was the condition, or any aspect of it, caused by or related to military service?

In addition, the report includes findings from six focus groups that were held to guide the development of the questionnaire as well as 45 in-depth telephone interviews conducted with respondents to the online survey. The focus groups were held in three cities—two in Washington, D.C. on May 20, two in San Antonio on May 24, and two in San Diego on May 25. The telephone interviews were conducted between July 30 and September 20, 2010.

The questionnaire was designed by Mathew Greenwald & Associates in collaboration with the National Alliance for Caregiving. It was also shaped by input from the team of knowledgeable veterans organization advisors listed in the acknowledgements. The full questionnaire is presented in Appendix A to this report.

The online questionnaire was launched on July 15 and closed on September 15, 2010. Caregivers of veterans were recruited to participate in the survey as early as March 5. Since privacy rules prohibit the VA from sharing the names of caregivers of veterans, a “snowball” sample approach was used, beginning with veterans service organizations who contacted their veteran members; they in turn passed the request to their caregivers. The project reached out to dozens of organizations across the country that have contact with and/or support caregivers of veterans, including the Department of Veterans Affairs, veterans service organizations (such as Paralyzed Veterans of America, Disabled American Veterans, and Wounded Warrior Project), the U.S. Administration on Aging, and many caregiving organizations. They were asked to disseminate information about the study and to invite caregivers to participate. They were all given a flyer that described the study and included a general link for accessing the survey online. In addition, those who requested it were sent hard copies of the survey so that it could be completed on paper and mailed in.

Between March 5 and July 15, caregivers who were interested in participating in the study were allowed to pre-register for the survey online. Pre-registered caregivers were sent one invitation and four reminders, each with a personalized survey link, over the course of the July 15 to September 15 survey period. Of the 330 qualified pre-registrants, 192 completed the survey and 11 terminated as not qualified, for a completion rate of 58% and a response rate of 62%. In addition, a total of 257 caregivers clicked into the general survey link and 13 responded by mail, bringing the total number of survey respondents to 462.

The questionnaire typically took 24 minutes to complete. As an incentive to participate, respondents were entered into a drawing in which ten participants were randomly selected to receive gifts of \$100 each.

Reading this Report

It is important to remember that all results in this study pertain to family caregivers of veterans *whose illness, injury or condition is in some way related to military service*. For shorthand, these caregivers are usually referred to in the report as “caregivers of veterans.”

The main graphics and tables in this report present results for all respondents to the online questionnaire. Occasionally, a mail respondent left a question unanswered; results for any such questions exclude non-respondents.

Significant differences between subgroups of veterans are shown as bulleted findings.

Differences between caregivers who provide care to older veterans and those who care for younger veterans coincide closely with differences between subgroups of caregivers defined by the war in which the veteran served. This report generally presents such findings in terms of the veteran’s age, partly because the specific war was not reported for all veterans, and also because some veterans served in multiple war periods.

All figures have been rounded. In addition, “don’t know” responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results of questions which allowed respondents to provide multiple responses may also add to greater than 100%.

Analyses that are based on input from focus group participants or in-depth interviewees are identified as “Qualitative Findings” throughout the report. In addition, quotes from any participants are presented in italics. All names have been changed in order to maintain the confidentiality of both caregivers and veterans.

This report periodically cites figures from the 2009 national study of caregivers entitled *Caregiving in the U.S.* and produced by the National Alliance for Caregiving in collaboration with AARP. All such figures reflect results from a subset of the study’s respondents—the 1,307 national caregivers whose care recipient is age 18 or older.



Key Findings and Recommendations

Basics of the Caregiving Situation

The typical caregiver of a veteran whose illness, injury or condition is service-related is a woman who is taking care of her husband or partner. In fact, 96% of these caregivers of veterans are women, and 70% provide care to their spouse or partner. This contrasts with the national picture of family caregivers where 65% are women and only 6% provide care to their spouse or partner.

Given the prevalence of spousal relationships, it is not surprising that caregivers of veterans are more than three times as likely as family caregivers in general to live in the same household as the person to whom they provide care (80% vs. 23%) and far more apt to be the primary caregiver (82% vs. 53%).

The veteran care recipients tend to be much younger than caregivers nationally, with 41% of caregivers saying the veteran is between the ages of 18 and 54.

Vignettes of Selected Caregivers

Candy

Candy's husband was a Navy SEAL in Vietnam. He was exposed to Agent Orange and he developed PTSD recently. She says, "My life turned a total 180. The plan was that when he graduated from college [after returning to school in his mid-40s]...then I was going to go back to school and complete my degree. He got sick and I watched my sturdy, handsome, tall, proud husband melt before my eyes...I hated him. I resented him. I was angry, and there was nobody I could talk to about it. He's a soldier. He's a warrior. Well, he went belly up and I'm still fighting."

Candy had to quit her job and put school plans on indefinite hold because her husband required full-time monitoring. The couple had to sell their house for financial reasons and moved to the country. One day Candy was out and called home. She asked the kids, "Where's your dad?" And they said, "Oh, he's down by the railroad tracks." She got home in time, but he was going to walk in front of the next train that came by.

	Caregivers of Veterans (n=462)	Caregivers of Adults Nationally (n=1,307)
Female caregiver	96%	65%
Spousal caregiver	70%	6%
Caregiver lives with care recipient	80%	23%
Primary caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

The youngest veterans requiring caregivers, those whose ranks are growing from Operation Iraqi Freedom and Operation Enduring Freedom in Afghanistan, pose a particular concern. One in four are being cared for by their parents (26%). As their parents age, they will likely need more caregiving support and, ultimately, caregiving responsibilities may need to be transitioned to others.

The conditions for which veterans need care differ greatly from the typical care recipient population. Large proportions of caregivers of veterans say the veteran has mental illness such as depression or anxiety (70%) or post traumatic stress disorder (PTSD) (60%), whereas nationally, mental or emotional health problems are reported by only 28%. Other top conditions reported by caregivers of veterans include traumatic brain injury (TBI) (29%), diabetes (28%), and paralysis or spinal cord injury (20%).

Of note, eight in ten caregivers (80%) report their veteran has two or more of the ten specific conditions asked about, and two-thirds (67%) name additional conditions such as bone, joint, or limb problems (24%), hearing or ear problems (12%), heart conditions (9%), neuropathy/nerve issues (9%), etc. Thus, strategies to inform, educate, and support caregivers must address multiple needs.

Care for a veteran whose condition is service-related is a longer-term endeavor than family caregiving typically is, with 30% of caregivers of veterans having been in their role for 10 years or more, compared to only 15% nationally.

Caregiving Activities and Burden of Care

Not only are caregivers of veterans in their role for a longer period, but their burden of care is also heavier—65% are in a high burden caregiving situation compared to 31% nationally. The increased burden is due to a greater likelihood of helping with Activities of Daily Living including dressing, bathing, feeding, and dealing with incontinence and with all of the Instrumental Activities of Daily Living¹ except for transportation.



¹ Instrumental Activities of Daily Living include housework, managing finances, transportation, grocery shopping, preparing meals, giving medications, and arranging/supervising paid services.

Impact of Caregiving

Perhaps because of their increased burden of care, caregivers of veterans report a greater impact of caregiving on their lives than caregivers in general do. Moreover, the caregivers of veterans who have PTSD, TBI, or mental illness such as depression or anxiety are even more likely to suffer many impacts of caregiving—on health, emotional stress, feelings of isolation, the caregiver’s marriage and children, and finances.

The heightened impact of providing care to a veteran is manifest in a number of ways. Overall, twice as many caregivers of veterans consider their caregiving situation to be highly stressful than do caregivers of adults nationwide (68% vs. 31%) and three times as many say there is a high degree of physical strain (40% vs. 14%). Of those who are currently married, separated, or divorced, three-quarters say caregiving or the veteran’s condition placed a strain on their marriage (74%). Among the 30% who have children under the age of 18 in the household, two-thirds report having spent less time with their children than they would like (69%) and 57% report that their children or grandchildren had emotional or school problems as a result of their caregiving or the veteran’s condition.

Providing care to a veteran with a service-related condition has widespread impacts on the caregiver’s health. Large proportions report increased stress or anxiety (88%) or sleep deprivation (77%). Healthy behaviors—such as exercising, eating habits, and going to one’s own doctor and dentist appointments on schedule—decline for roughly six in ten, and similar proportions have weight gain/loss or experience depression.

Of the caregivers of veterans who were employed at some point while serving as a caregiver, a large share experience employment changes that result in a loss of income or benefits. Six in ten (62%) cut back the number of hours in their regular schedule. Half (47%) stopped work entirely or took early retirement, while fewer than one in ten nationally reported either of these impacts. Half of caregivers of veterans feel a high degree of financial hardship (50%), compared to 13% nationally.

	Caregivers of Veterans (n=462)	Caregivers of Adults Nationally (n=1,307)
High emotional stress (4+ on 5-point scale)	68%	31%
High physical strain (4+ on 5-point scale)	40%	14%
Stopped working or took early retirement (among those who worked while caregiving)	47%	9%
High financial hardship (4+ on 5-point scale)	50%	13%

Caregiving Challenges

The top challenges faced by caregivers of veterans—each experienced by at least two-thirds of caregivers—are:

1. Not knowing what to expect medically with the veteran's condition
2. Not being aware of Department of Veterans Affairs (VA) services that could help
3. Not knowing how to address PTSD or mental illness (among those who report that such a condition is present)
4. Difficulty getting through bureaucracies in order to obtain services
5. Not knowing where to obtain financial assistance
6. Not knowing where to turn to arrange a break from caregiving
7. Not knowing where to obtain specialized care

All but the first of these challenges are more commonly noted by caregivers of veterans who have TBI.

Support Received

About six in ten caregivers of veterans say that the veteran has received help from other unpaid caregivers (58%), while only one-third have received help from paid caregivers (33%). Only 15% have received respite services from the VA or some other community organization within the past 12 months.

A care manager is a potential support resource for half of caregivers who say their veteran has one or more (48%). Two-thirds (65%) of caregivers of veterans who have a care manager say that person has been at least *somewhat* helpful in locating, arranging, and coordinating care and resources for the veteran, although it is a smaller share (43%) who feel the care manager has been helpful in finding support for the caregiver her/himself.

Contrary to what one might expect, the presence of one or more care managers does not appear to ease caregivers' situations in terms of lowering stress, the likelihood of isolation, the difficulty of finding resources that they seek, or impacts on employment. However, the likelihood of the caregiver receiving respite care does increase in relation to the number of care managers.

Three in ten caregivers report that the VA or Department of Defense military systems proactively gave them information or links to information to help them understand the veteran's condition, treatment, or services (29%). This appears to help caregivers feel more confident in their first six months of caregiving.

Information Sources

Word of mouth is the source of information caregivers of veterans most commonly turn to when they look for caregiver resources and information. It is *very* or *somewhat* helpful to six in ten of those who have used it (63%). The organizations that more caregivers of veterans turn to than any other are the VA Health Administration, the VA Benefits Administration, and non-VA health providers. At present, those who have used these sources of information are notably more likely to consider the non-VA providers as helpful (73%) than the VA (43% and 41% for the two administrations, respectively).

Three other sources of information are not used as frequently, but each is considered as helpful by at least two-thirds of caregivers: online forums, groups, or blogs; disease-specific organizations; and in-person support groups.

Helpful Programs and Services

Caregivers of veterans are very receptive to 15 prospective programs; the programs fall into five clusters:

Information and Training

- A list of varied types of information or services that caregivers may need, along with phone numbers and Web sites of the VA departments and community organizations that provide them
- A list of organizations that provide financial assistance for veterans or their caregivers
- Caregiver training on how to do caregiving tasks safely and effectively, and how to take care of oneself

Support and Information

- A mentor who has been a caregiver of a veteran
- A support group or online discussion group for caregivers of veterans with conditions similar to the veteran being cared for
- A telephone help line for caregivers of veterans
- Counseling or therapy for the caregiver or his/her family

Help Coordinating Care or Obtaining Services

- Having a single care manager as a source of information for all of the veteran's needs [among those who have no care managers or more than one]
- Help for the caregiver and his/her family to plan transitions [e.g., out of a facility, from one city to another]
- An advocacy service that helps the caregiver get what s/he needs if resistance or "red tape" is encountered

Respite and Relief

- Having access to a small group of local volunteers to assist the caregiver with tasks of his/her choosing
- Periodically having someone qualified to come in and give the caregiver a break
- A transportation service for the veteran's medical appointments

Miscellaneous

- Having a health professional explain the veteran's condition to family/friends to understand the situation better
- Legal assistance to prepare a medical power of attorney or advanced directives



Recommendations

1. Provide Training and Information for Common Veteran Conditions

- Create condition-specific caregiver information packets and training, and provide them to caregivers when they first take on their caregiving role.
- Offer a toll-free 24-hour phone line with support, information, and referrals.

2. Harness the Word of Mouth by Helping Caregivers Help One Another

- Develop a central website for caregiver support groups, forums, and blogs.
- Establish a caregiver peer mentoring program.

3. Teach Caregivers About Resources That Are Available

- Ensure that all caregivers receive a directory of VA programs and services as well as other governmental and community caregiver resources.
- Teach caregivers about advocacy resources and methods.
- Create a list of financial assistance resources available to veterans and their caregivers.
- Direct caregivers to legal assistance.
- Facilitate caregiver searches for specialized care facilities.

4. Help Caregivers Find Respite and Relief

- Develop programs that connect caregivers of veterans with volunteers.
- Help caregivers find respite care.
- Improve veteran transportation services.

5. Improve Dissemination of Existing Resources

- Package existing information in a way clearly meant for family caregivers, with “family” defined broadly to include those who are neither spouses nor parents of the veteran.
- Review existing materials to ensure that they meet caregivers’ needs, involving caregivers in the review process.
- Improve methods for connecting caregivers to existing information.

6. Sensitize Health Care Providers to Caregivers’ Role

- Periodically sensitize health providers about the important role that caregivers play in providing care to veterans.
- Ensure that caregivers are shown how to properly administer medical treatments, care, or medications.
- Empower care managers to provide services for the caregivers themselves.

7. Provide Other Information and Tools to Support Caregivers

- Help caregivers plan for veterans’ transitions.
- Explain veterans’ condition to other family members.

Vignettes of Selected Caregivers

Doreen

Doreen’s husband, a veteran of Operation Iraqi Freedom, suffers from a traumatic brain injury and has had his right leg and right arm amputated. Doreen helps her husband with prosthetic appointments, takes care of the house, and as she says, “chases after” their one-year-old son. Her husband’s memory has been severely affected by the TBI; she says, “If it’s been more than 48 hours, it’s gone.” To help him remain as independent as possible, she says, “Any time he needs to do something, I have it set into his “smartphone” or his Google calendar so it will automatically pop up on his computer screen to let him know what’s next.”

Socializing has become difficult because she does not think her day-to-day experiences are the subject matter for chit-chat with friends over lunch. She sometimes feels she has nothing to contribute to conversations with others. She says this makes her feel isolated and discourages her from going out with friends at all. What Doreen would really like is to have someone to talk to who understands and can relate to her caregiving and life experiences. But as resourceful as she has been for her husband, Doreen has run into dead ends when looking for resources for herself. “I spent hours and weeks looking and there was just nothing there. No support groups, no online forums, no online communities. Nothing.”

Just recently, she may have found an organization that can help—the Amputee Coalition of America—a group that hosts a convention for people in similar situations. Doreen was unable to travel to the group’s convention this year because she is pregnant, but she says the group looks very promising, and she looks forward to getting together with others like herself in the future.



Detailed Findings

A. Basics of the Caregiving Situation

Veteran's Main Problem or Illness

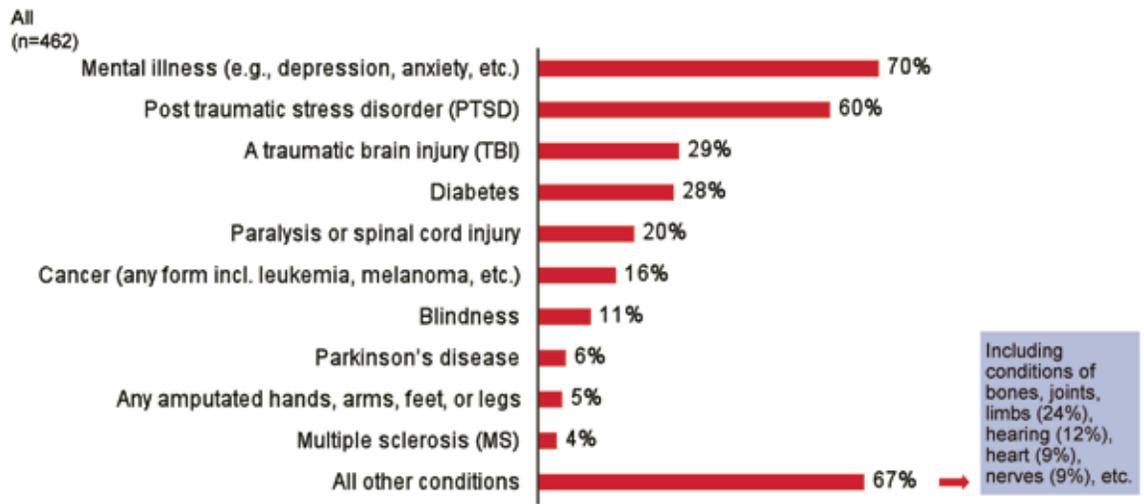
Caregivers² were asked whether the veteran to whom they provide care has one of ten specific health conditions, and they were allowed to write in any additional conditions. Of the ten conditions asked about, the most prevalent is mental illness, reported by 70%.³ This is followed closely by post traumatic stress disorder (PTSD) (60%). Almost three in ten say their veteran has a traumatic brain injury (TBI) (29%) or diabetes (28%). One in four caregivers volunteer that the veteran has injuries to bones, joints, or limbs (24%).

² Throughout this report, any reference to “caregivers” or “caregivers of veterans” refers to the respondents who all provide care to a veteran whose illness, injury, or condition is related to military service.

³ The survey asked about the presence of “mental illness (e.g., depression, anxiety, etc).” From this point forward, the report uses the term “depression/anxiety” as shorthand for this mental health condition.

Figure 1: Veteran's Condition

Q8. Does the veteran you care for have...?



- The types of health conditions from which the veteran is suffering vary in close relation to the veteran's age and the war in which he or she served. The presence of diabetes or cancer is increasingly reported by caregivers of older veterans and those serving in Vietnam or earlier. [Note that both conditions are more common among these care recipient veterans than in a similarly-aged general population.] Depression/anxiety, PTSD, and spinal cord injuries are more common among younger veterans, particularly those who served in Vietnam or later. The proportion of caregivers reporting TBI jumps among those caring for the youngest veterans who served in recent wars.

Figure 2: Percentage with Selected Conditions, by Age of Veteran

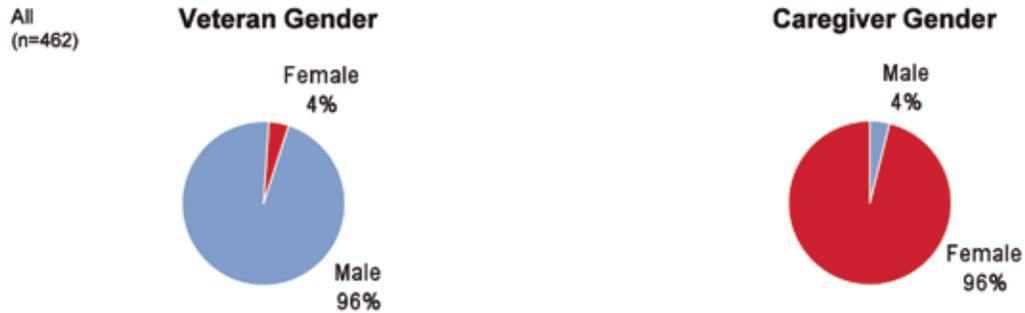
	Age of Veteran		
	Less than 45	45 to 64	65+
Mental illness (e.g., depression, anxiety, etc.)	78%	78%	56%
Post traumatic stress disorder	79%	67%	36%
Traumatic brain injury	61%	21%	10%
Diabetes	6%	39%	36%
Cancer	4%	16%	27%
Parkinson's disease	1%	4%	13%

Gender of Caregiver and Veteran

The vast majority of the veterans who are being given care are male (96%), and nearly all of the caregivers are female (96%).

Figure 3: Gender of Veteran and Caregiver

Q5. Is the veteran male or female?
D1. What is your gender?

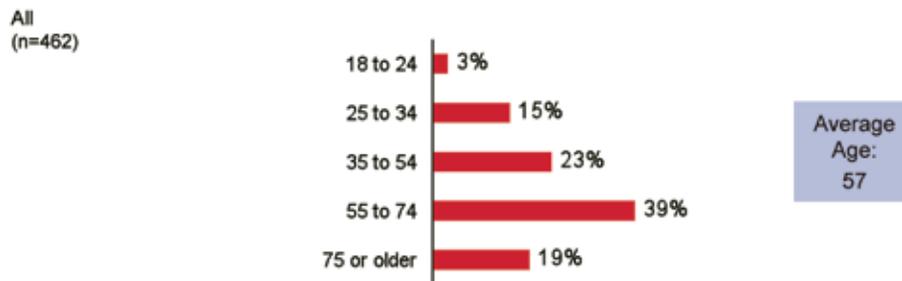


Veteran's Age and Period of Service

One in five veterans being cared for is under age 35 (18%), and another quarter are between the ages of 35 and 54 (23%). Two out of five fall into the 55 to 74 age range (39%). One in five is age 75 or older (19%).

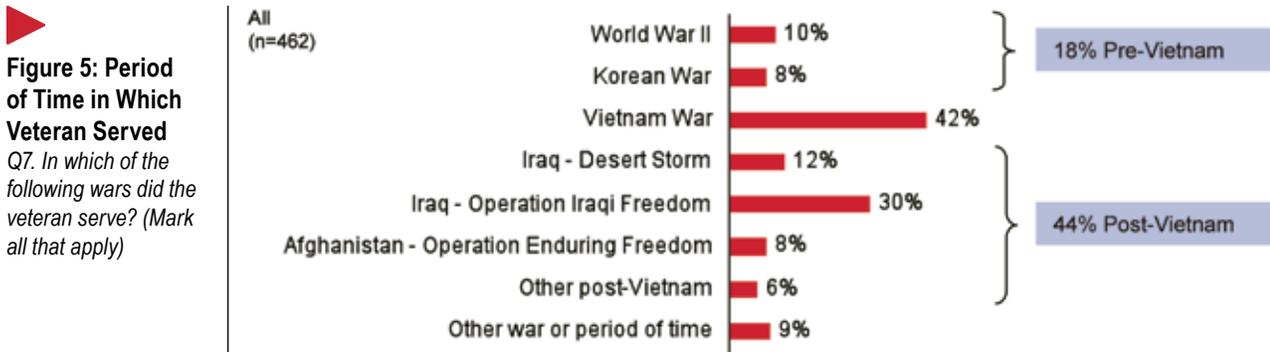
Figure 4: Age of Veteran

Q6. How old is the veteran you care for?

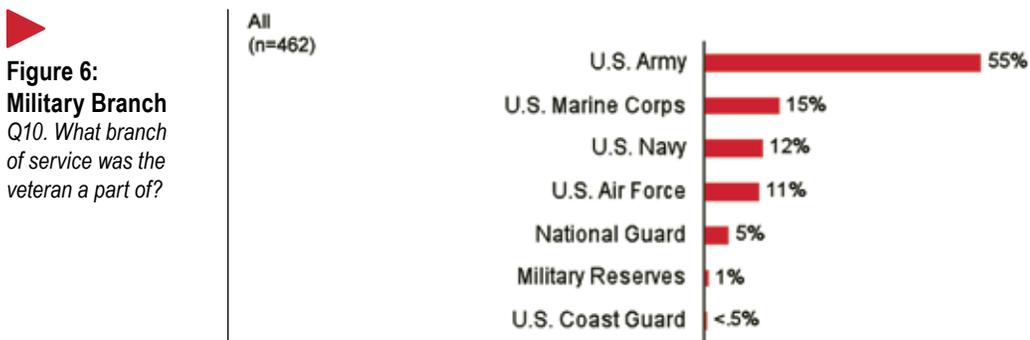


Detailed Findings

Caregivers of Vietnam veterans are the most numerous among the survey respondents (42%). Nearly one in five respondents (18%) provides care to a veteran who served during an earlier war—World War II or the Korean War, and 44% say their veteran served during a post-Vietnam war or period.

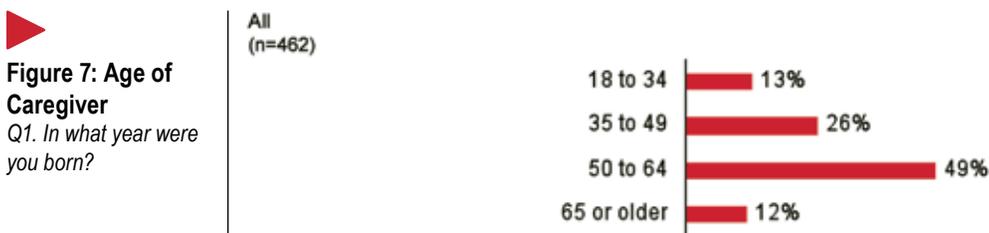


More than half of the caregivers surveyed indicate that the veteran they care for was a part of the U.S. Army (55%). Smaller shares are veterans of the U.S. Marine Corps (15%), the U.S. Navy (12%), or the U.S. Air Force (11%), and 6% were in either the National Guard or military reserves.



Age of Caregiver

Six out of ten caregivers of veterans surveyed are at least 50 years of age (61%), including one in eight who is 65 or older (12%).



- As one might expect, the age of the caregiver rises in relation to the number of years the caregiver has been in his or her role. Of the new caregivers who have been in their role for two years or less, only 6% are 65 or older, compared to 15% of those who have been in their role for five years or more.

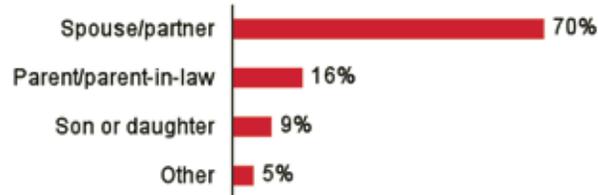
Veteran's Relationship to Caregiver

Most caregivers say the veteran they care for is their spouse or partner (70%). Far fewer, only 16%, say they are caring for a parent or parent-in-law, and about one in ten indicate that they are caring for their son or daughter (9%). These relationships differ from caregivers in general; nationally, only 6% of caregivers are providing care to a spouse or partner. Of note, not all family caregivers of veterans are actual family members; they may be friends, neighbors, or other non-relatives.

Figure 8: Veteran's Relationship to the Caregiver

Q11. What is the veteran's relationship to you? Is he/she your...

All
(n=462)



- Of course, the veteran's age is associated with the relationship between the caregiver and the veteran. Among the caregivers who are caring for a veteran who is 65 or older, a disproportionately large share are providing care to their parent or parent-in-law (38%). Of the caregivers whose veteran is 45 to 64, nearly nine in ten are providing care to a spouse or partner (88%).

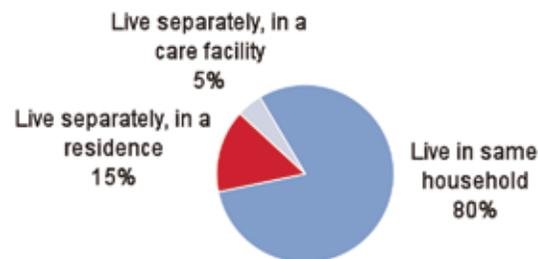
Where Veteran Lives

Given the prevalence of spousal relationships, it is not surprising that caregivers of veterans are more than three times as likely as family caregivers in general to live in the same household as the person for whom they provide care (80% vs. 23%). Others report that the veteran lives in a separate household (15%) or in a care facility (5%).

Figure 9: Living Situation

Q14. Do you and the veteran currently live in the same household?
Q15. [IF NO TO Q14] Is the veteran currently staying in a medical center, nursing home, or some other care facility?

All
(n=462)

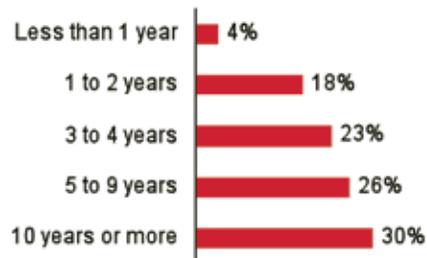


Duration of Care for Veteran

Most caregivers surveyed have been in their role for a considerable length of time—more than half (56%) report that they have been providing care to the veteran for at least five years, including 30% who have been doing this for 10 or more years. By contrast, one in five has been a caregiver to their veteran for two years or less (21%).

Figure 10:
Duration of Care for Veteran
Q12. For how long have you been providing care for this veteran?

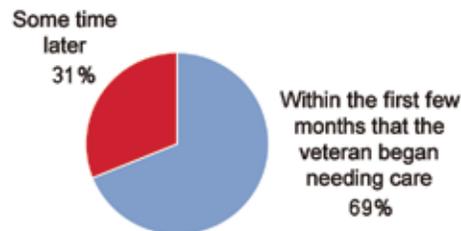
All
(n=461)



Seven out of ten caregivers say that they first took on a caregiving role within the first few months that the veteran began needing care (69%). The remainder took on this role some time later (31%).

Figure 11: When Caregiving Began
Q13. When did you first take on a caregiving role?

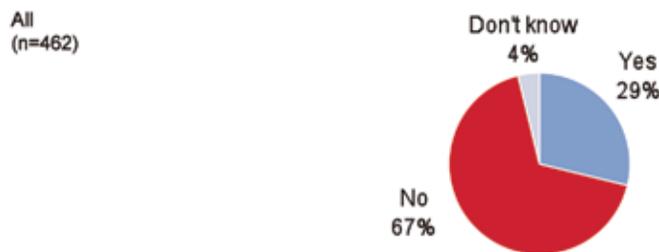
All
(n=462)



Choice in Taking on Caregiver Role

Only 29% of caregivers of veterans feel they had a choice in taking on the responsibility of caring for their loved one. By comparison, nationally 57% of caregivers do.

Figure 12: Choice in Taking on Caregiver Role
Q39. Do you feel you had a choice in taking on the responsibility of caring for the veteran?



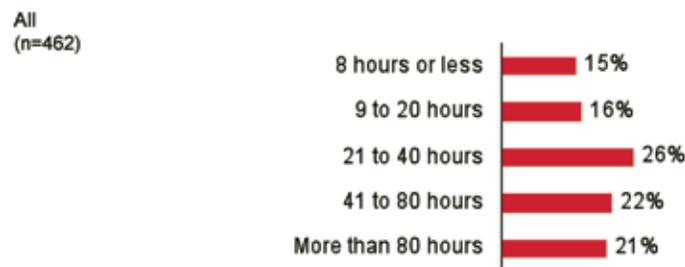
Caregivers of veterans who feel, for whatever reason, they did not have a choice in becoming a caregiver are more likely to report impacts on their lives in terms of emotional stress, isolation, physical strain, financial hardship, children's emotional problems, and work impacts. They are also far less likely to say the experience is fulfilling for them or that the knowledge and skills they are gaining give them a sense of reward. These effects are evident even though their burden of care appears to be equivalent to those who feel they did have a choice.

B. Caregiving Activities and Burden of Care

Hours of Care Provided

Most caregivers of veterans (69%) report typically spending at least 21 hours per week helping the veteran. This includes 43% who spend more than 40 hours per week—three times the share of caregivers nationally who do (12%).

Figure 13: Hours of Care Provided
Q17. In a typical week, about how many hours in total do you spend helping the veteran in all of the ways you just indicated?



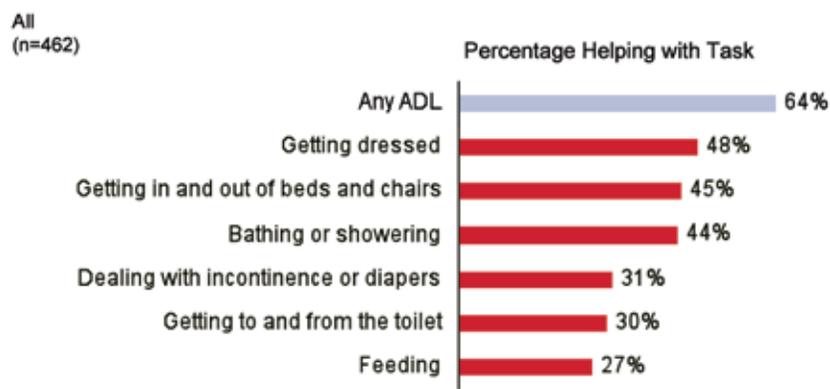
- Caregivers whose veteran has paralysis or diabetes are nearly twice as likely as their counterparts to spend more than 80 hours per week providing care.
- Those providing care to a spouse/partner are in the most time-intensive situations—half (50%) spend more than 40 hours per week, compared to 32% of those providing care to their child and 24% of those who have some other relationship to the veteran.



Help with Activities of Daily Living

Six in ten caregivers (64%) report that they assist the veteran they care for with one or more Activities of Daily Living (ADLs). The most common of these activities are help with getting dressed (48%), getting in and out of beds and chairs (45%), and bathing or showering (44%). The proportions who help with dressing, bathing, incontinence care, and feeding are larger than the shares of caregivers nationwide who help with these ADLs.

Figure 14: Help with Activities of Daily Living (ADLs)
Q16. With which of the following tasks do you help the veteran?

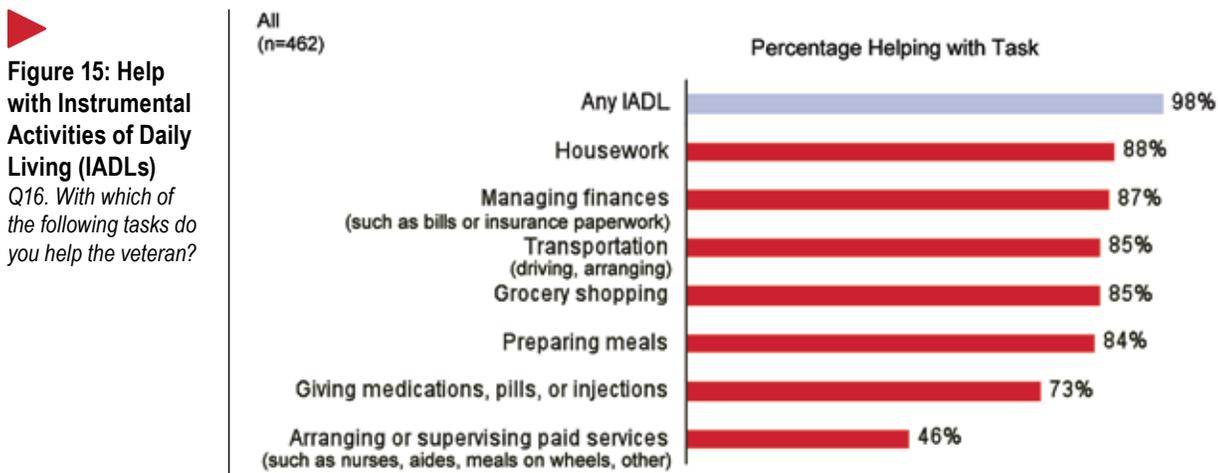


- The proportions of caregivers who help with each of the ADLs rise in relation to the veteran's age.
- Caregivers of veterans with spinal cord injuries or paralysis are more likely to report helping with each ADL, and those caring for someone with diabetes are more apt to say they help with getting the veteran in and out of beds and chairs, bathing, and dealing with incontinence.
- Those whose veteran has PTSD or depression/anxiety are less likely to help with each of the ADLs.

Help with Instrumental Activities of Daily Living and Other Supportive Activities

Virtually all caregivers surveyed say they help the veteran they care for with Instrumental Activities of Daily Living (IADLs) (98%). More than eight in ten caregivers help their veteran with the following IADLs: housework (88%), managing finances (87%), transportation (85%), grocery shopping (85%), and preparing meals (84%). Seven in ten assist in administering medications or injections (73%). A smaller, but still considerable share (46%), help arrange or supervise paid services.

Caregivers of veterans are more likely than caregivers nationwide to help with each of the IADLs except transportation.



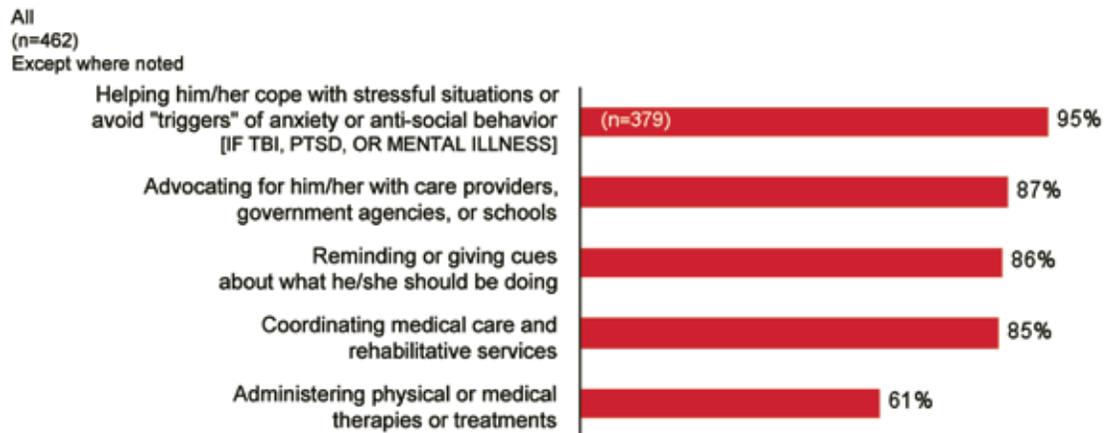
- Caregivers are more likely to report helping with finances when their veteran has TBI (93% vs. 85% without TBI).
- Those who provide care to a veteran with paralysis or a spinal injury are more apt than others to name meal preparation (91% vs. 82%), giving medicines (85% vs. 71%), and managing paid services (56% vs. 43%) as ways in which they help. Help with medication is also more common among those caring for someone with diabetes (83% vs. 70% without diabetes).
- The likelihood of helping with several IADLs increases as the veteran's age increases: transportation (from 77% for veterans under age 45 to 93% for veterans age 65 or older), medication (65% to 79%), and arranging paid services (31% to 62%).

Detailed Findings

In addition to helping with ADLs and IADLs, caregivers help the veterans with other aspects of their care and with day-to-day living. Nearly all of those who care for a veteran with TBI, PTSD, or depression/anxiety say they help him or her cope with stressful situations or avoid “triggers” of anxiety or anti-social behavior (95%). Nearly nine out of ten of all caregivers of veterans say they advocate for him/her with care providers, government agencies, or schools (87%), remind or give cues about what he/she should be doing (86%), and coordinate medical care and rehabilitative services (85%). Fewer, but still a considerable share, administer physical or medical therapies/treatments (61%).

Figure 16: Help with Other Supportive Activities

Q16. With which of the following tasks do you help the veteran?



Avoiding Triggers

I have always called ahead and made sure that wherever we're going understands that he can't wait in the waiting room long, and if he has to, we will end up having to leave...we don't typically go anywhere at night or on the weekends, because it's too busy. If we are going to go to a movie, we go usually on a Tuesday afternoon when we are hopefully the only people in the theater. We always do everything way early, because it takes a long time to do anything with him. If you rush him, he gets very overwhelmed, over-stimulated, and stressed.—Caregiver #3

He calls me, on average, 10 times a day when I'm at work every day, saying that something has happened and he can't deal with it anymore. If our Arrowhead water delivery isn't there on time, he starts panicking. He calls them and maybe he waits on hold, and he just really is going to have a major breakdown for something that seems minor to you or me. He can't handle it. So I'll tell him to give me the number, I'll call, don't worry about it.—Caregiver #8

Advocacy

An example of advocacy was getting his Social Security benefits. He wasn't going to apply, and it was all just too hard and too overwhelming. I found a lawyer and supplied all the information and the medical records and got him to the appointments and pulled it all together and gave testimony.—Caregiver #32

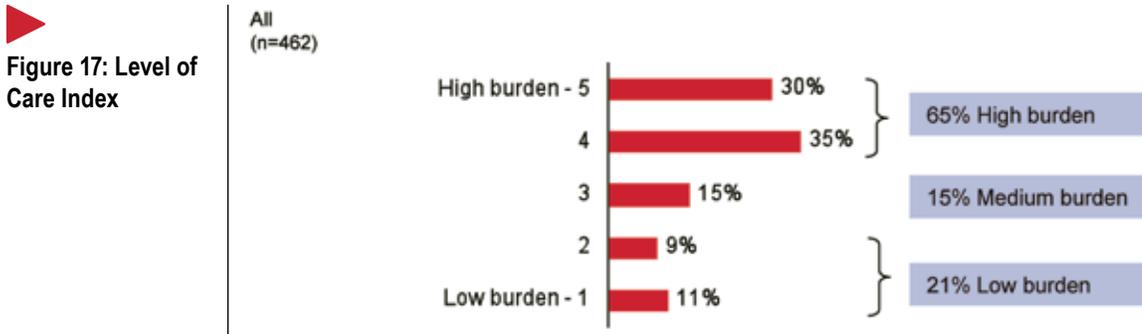
I have to push everybody and nobody's responding...for different housing. Young people, 30-year-old people, do not belong in a nursing home full of 80-year-old people. When I say something to the VA, they say, "Well, we don't do group homes"...I'm trying to get a group home built for four or six younger veterans.—Caregiver #4

Reminders and Cues

If he doesn't have a list to go off of, he is not going to remember...if it's been more than 48 hours, it's gone...any time he needs to do something, I have it set into his "smartphone" or his Google calendar...if it's not in there, it doesn't exist. For cooking, everything has to be written out, even if he has made the item 15 to 20 times. At the grocery store, if it's something not generic like milk or bread, he needs a picture of it. So if I send him to the store for baby formula, I would take a picture of the formula with his iPhone and then put on there, "formula, see photo," even though we've used the same formula for 12 months.—Caregiver #5

Burden of Care

Two-thirds of the caregivers who responded to this survey have a high burden of care (65%), 15% have a medium burden, and 21% have a low burden.⁴ Nationally, only 31% of caregivers have a high burden.



- The caregivers who have a higher burden of care tend to be older, on average (53 years of age, compared to 49 for those with a medium to low burden of care).
- They are also more likely to be spousal/partner caregivers (78%) than are those with a medium burden of care (64%) or a low burden (49%).
- Caregivers whose veteran has paralysis or a spinal injury are more likely than those without such a condition to be in a high burden situation (80% vs. 61%).
- Longer-term caregivers—those who have been in their role for five years or more—are also more apt to have a higher burden (70%) than are those who have been caregivers for two years or less (55%).
- Interestingly, the burden of care rises as the level of education falls; 58% of college graduates have a high burden, while 84% of those with no more than a high school education do. This is in spite of the fact that the different educational groups appear to be equally likely to be the primary caregiver and to report the involvement of other unpaid or paid caregivers.

A summary of the number of hours of care provided and the average number of ADLs and IADLs performed at each level of care is as follows:

Figure 18: Hours of Care and Counts of ADLs, IADLS by Burden Category

	Low Burden (n=95)	Medium Burden (n=69)	High Burden (n=298)
% More than 20 hours/week	2%	64%	91%
Number of ADLs – out of 6 total	0.1	0.9	3.3
Number of IADLS – out of 7 total	3.7	5.0	6.1

⁴ The measure of the burden experienced by caregivers is based on a Level of Care Index first developed in the 1997 study Family Caregiving in the U.S. and is replicated in this study. The index is based on the number of hours of care given, as well as the number of ADLs and IADLS performed.

Presence of Additional Care Recipients

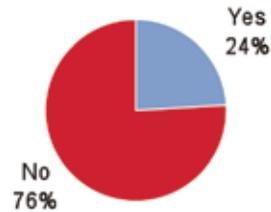
One in four caregivers of veterans report that they also provide care to another person with special health needs.



Figure 19: Caregiver for Others

Q36a. Are you also an unpaid caregiver for anyone else with special health needs other than the veteran?

All
(n=462)



- Those who provide care to a parent or a parent-in-law are twice as likely as others to say they care for at least one other person (45% vs. 21%).
- Those with a low burden of care for the veteran are more likely than those with a medium or high burden to provide care to another person with special health needs (34% vs. 22%).

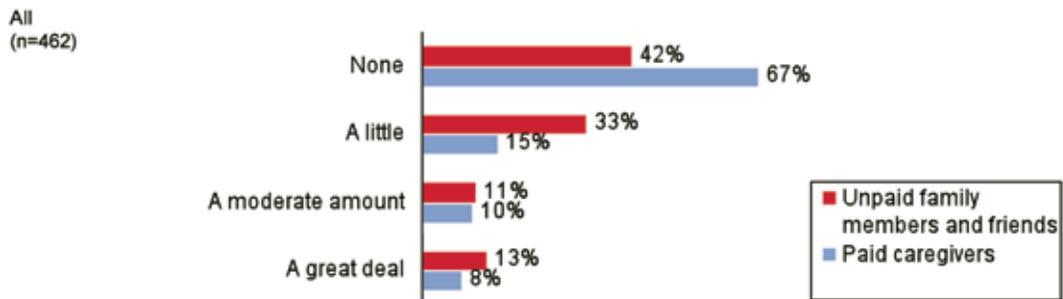
C. Presence of Other Caregivers

Presence of Other Unpaid and Paid Caregivers

Two-thirds of caregivers report that the veteran they care for has not received any care from paid caregivers (67%). Even unpaid help is not very common. Only one-quarter of caregivers indicate that the veteran has had at least a *moderate* amount of care given by other unpaid family members or friends (25%).

Figure 20: Amount of Unpaid and Paid Help

Q19. How much caregiving has been provided to the veteran during the past 12 months by...
 a. Other unpaid family members and friends?
 b. Paid caregivers who help with daily activities (e.g., home health aide/nurse, personal assistant, adult day care)?



- Half of spousal/partner caregivers indicate there is no other unpaid help (50%), compared to half as many of the caregivers who have some other relationship to their veteran (22%).
- Those who have given care to the veteran for at least three years are more likely than shorter-term caregivers to say there are no other unpaid caregivers (45% vs. 29%).
- Caregivers whose veteran has PTSD are also more likely than others to be the sole unpaid caregiver (47% vs. 34%).
- Caregivers who have children under the age of 18 in their household are more likely than those without children at home to say there is no paid care (81% vs. 61%).

Qualitative Findings

Those who are fortunate enough to have family members who help with the caregiving responsibilities typically name their own siblings, parents, or adult children as the people who help. They tend to provide periodic relief rather than substantial ongoing caregiving.

When no other family members provide a significant amount of help to the caregiver, it tends to be because they live out of town or are busy with jobs and children.

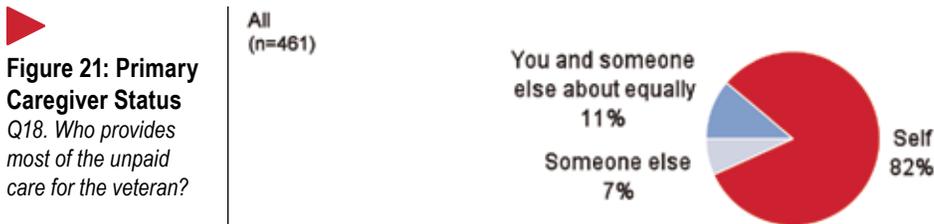
My son and his wife both work full time and part time, and anytime I need their help and ask for their help they will do it. But as far as them going to do Annette's therapies and stuff, they don't have the time. They're always here when I bring Annette home, and they always stay until I get her back in the van. If I'm not around and she needs something, they'll pick it up for her and take it to her. It's hard enough to raise a family and work full and part time and do all the chasing you do with three kids.—Caregiver #4

Occasionally, I'll have one of our sons come in from out of town and stay for a week and let me go away to my cousins' in Florida and do nothing.—
Caregiver #11



Primary Caregiver Status

Eight out of ten caregivers who responded to this survey say that they are the person who provides most of the unpaid care to the veteran (82%), whereas nationally, a notably smaller share (53%) report they are. One out of ten says that they and another individual share this responsibility equally (11%). Only 7% indicate that someone else provides the majority of the unpaid care for the veteran.

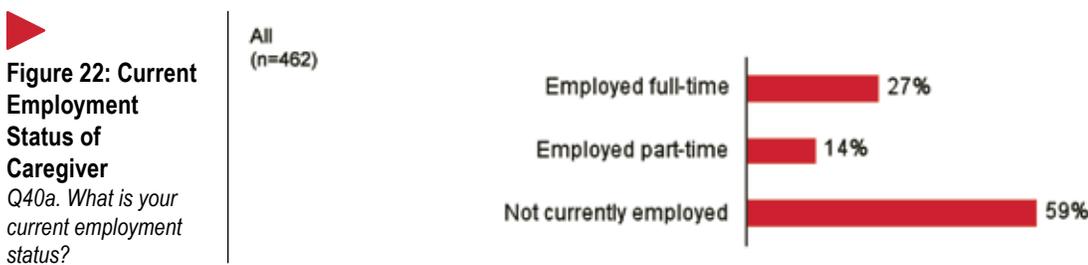


- Caregivers who have been in their role for at least three years are more likely than shorter-term caregivers to be the primary caregiver (86% vs. 69%). The shorter-term caregivers are more likely to share responsibilities equally with someone else (21% vs. 8%).
- Those providing care to a veteran under the age of 65 are also more likely to be the primary caregiver (86% vs. 74%). Those providing care to the older veterans are twice as likely as their counterparts to share the unpaid care about equally with someone else (16% vs. 8%).
- Nearly all of those who provide care to a spouse or partner are the primary caregiver (93%), followed by caregivers who are taking care of their child (76%) and those providing care to a parent or parent-in-law (55%). Only 32% of those providing care to some other relation say they provide most of the unpaid care.

D. Impact of Caregiving on Work

Employment Status and Caregiving

Six in ten caregivers of veterans are not currently employed (59%), while one-quarter are employed full time (27%) and 14% work part time.



- Subgroups of caregivers who are more likely to be employed full time include:
 - Those who have been providing care for no more than two years (38% vs. 24% of longer-term caregivers)
 - Those with a college education (39%), compared to 11% of those with no more than a high school diploma
 - Those with a low burden of care (53%), relative to 32% of those with a medium burden and 18% of high burden caregivers

Work Accommodations Due to Caregiving

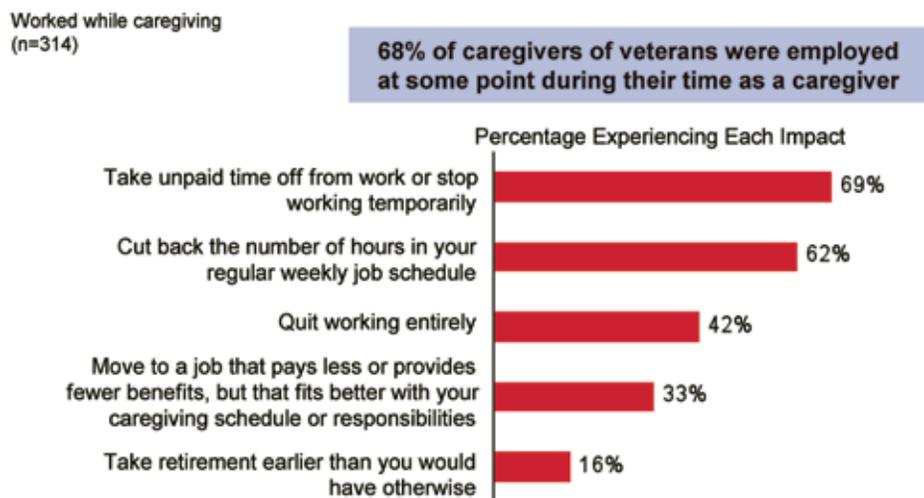
Two-thirds of caregivers of veterans have been employed at some point since they began helping the veteran they care for (68%).

Given the challenge of balancing employment with any time-consuming activity outside of work, it is not surprising that becoming a caregiver results in employment changes or adjustments. Caregivers were asked about five specific changes that would each result in a loss of income or benefits. The change seen most often among those who worked at some point since they have been a caregiver is taking unpaid time off from work or stopping work temporarily (69%), followed by cutting back the number of hours worked per week (62%). Nearly half went so far as to stop working entirely or to take early retirement (47%).⁵

At first, I didn't have a problem with the job. They were very understanding. After a while, it all becomes, "This is a business." It was said that [my caregiving activities] were not my responsibilities and that I should vacate that role...or I would lose my job...I was very upset and I just resigned. I took another job...that is very accommodating...but I took a severe pay cut...25% to 30%...and I lost health and dental.—Focus Group 5

Figure 23: Work Accommodations Due to Caregiving

Q40. Have you been employed at any time since you began helping the veteran you care for?
Q41. As a result of caregiving for the veteran, did you ever...



- As the length of time a caregiver has been providing care increases, so does the likelihood that the caregiver will move to a job with fewer benefits, quit working entirely, or take early retirement.

⁵ Note that some caregivers reported both quitting working entirely and taking early retirement. The proportion who stopped work as a result of caregiving in either of these two manners is 47%.

 **Figure 24:**
Percentage
Experiencing
Each Employment
Impact, by
Duration of Care

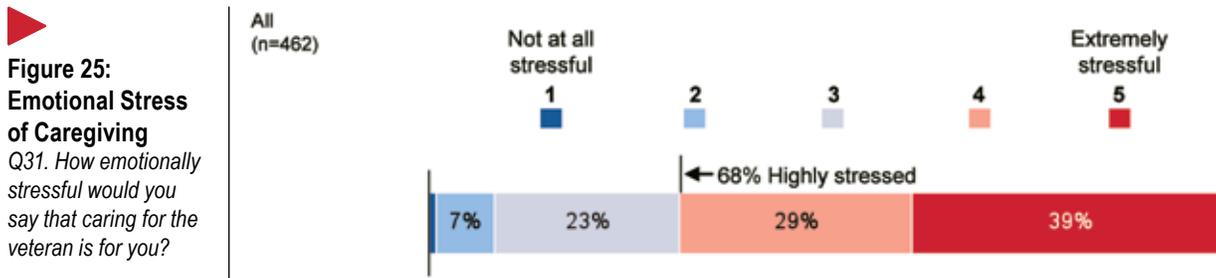
	Duration of Care		
	2 years or less	3 to 4 years	5 years or more
Moved to a job that pays less or provides fewer benefits, but that fits better with caregiving schedule or responsibilities	19%	37%	37%
Stopped working (Net)	25%	40%	57%
Quit working entirely	24%	38%	49%
Took retirement earlier than would have otherwise	5%	8%	23%

- Those more likely to stop working include caregivers of a veteran with depression/anxiety (50% vs. 37% of those without this condition), diabetes (57% vs. 43%), and paralysis or a spinal cord injury (60% vs. 44%).

E. Strain and Stress of Caregiving

Emotional and Physical Stress of Caregiving

When asked to rate how emotionally stressful it is to provide care to their veteran, two-thirds of caregivers surveyed (68%) indicate that they are highly stressed (giving a rating of 4 to 5 on a 5-point scale). This is twice the proportion of caregivers nationally who feel as stressed (31%).



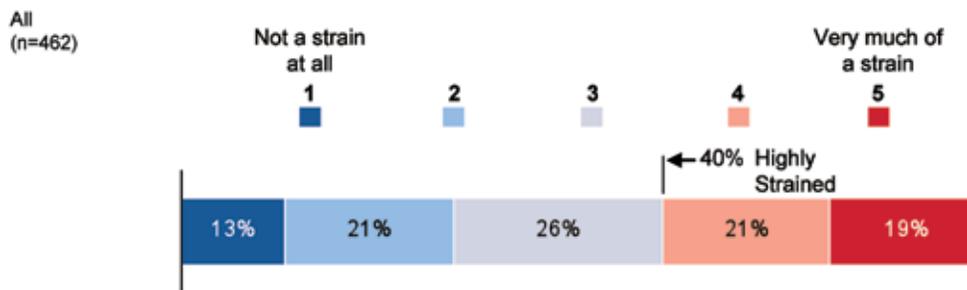
- Caregivers of veterans who were mobilized members of the military reserves or National Guard are more apt than those whose veteran was on active duty to report a high level of emotional stress (93% vs. 66% rate stress 4 or 5). [Note: n=27 for reservists/Guard.]
- Perhaps because of the emotional nature of depression/anxiety and PTSD, caregivers whose veterans have these conditions are also more likely to experience high emotional stress (PTSD: 74% vs. 58%; depression/ anxiety: 75% vs. 52%). TBI shows a similar pattern (77% vs. 64%).
- High burden caregivers also tend to report greater stress (73% rating it 4 to 5, compared to 55% of low burden caregivers).
- Caregivers of veterans under the age of 65 are more likely to report high stress than are caregivers of older veterans (72% vs. 60%). This effect is apparent even when controlling for the presence of PTSD and TBI which occur with greater frequency among younger veterans.
- Caregivers with household incomes less than \$50,000 are more apt to say they feel high emotional stress than are those with greater incomes (72% vs. 63%).

I am pretty much just worried about Nate all the time...If he has a seizure and he is by himself, how do you deal with it? What do you do? He speaks whatever he thinks, and he swears like a sailor, but 10 times worse. We have to tell him, "Nate, language." I worry about him saying the wrong thing to the wrong person, or if he is out in town at Wal-Mart and somebody looks at him. I worry about him all the time. There is no rest or peace from worrying about my child.—Interviewee #22

Detailed Findings

Four out of ten caregivers of veterans indicate that their caregiving responsibility causes them a high degree of physical strain (40% giving a rating of 4 or 5 on a 5-point scale), compared to only 14% nationally.

Figure 26:
Physical Strain of Caregiving
Q32. How much of a physical strain would you say that caring for the veteran is for you?

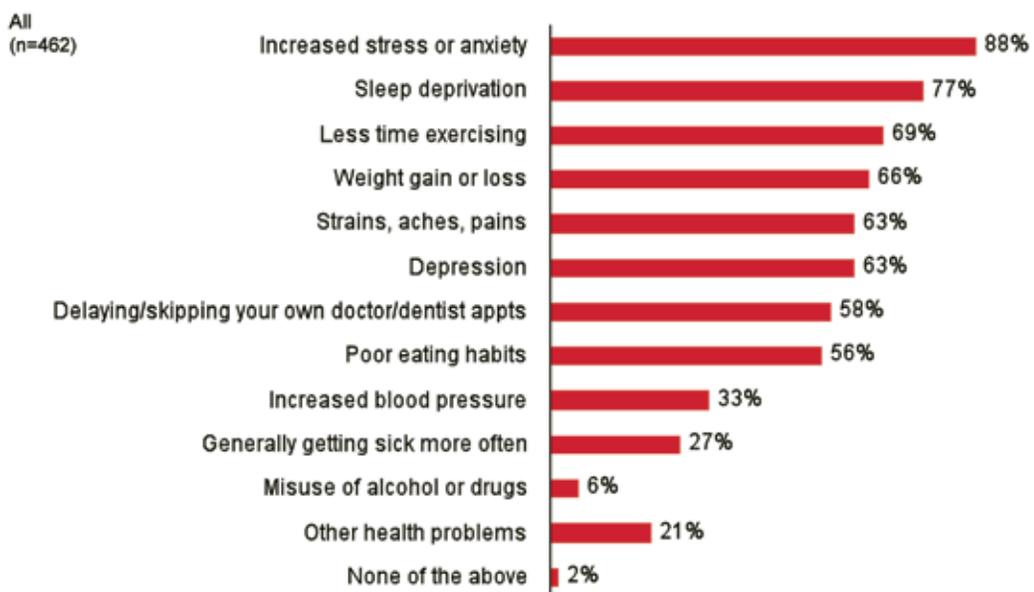


- High burden caregivers are three times as likely as low burden caregivers to experience significant physical strain (51% vs. 17% rating strain 4 to 5).

Impact on Caregiver's Health

Nearly all caregivers of veterans experience some sort of impact on their health, with stress or anxiety being most prevalent (88%), followed by sleep deprivation (77%). Preventive health care also suffers for many, in that two-thirds spend less time exercising (69%), 58% delay or skip their own doctor or dentist appointments, and more than half lapse into poor eating habits (56%). Perhaps as a result of these behavioral changes, 66% gain or lose weight and 63% suffer from depression. Six in ten also experience strains or aches (63%).

Figure 27:
Health Effects of Caregiving
Q34. As a result of becoming a caregiver, which of the following health problems, if any, have you experienced? (Please select all that apply)



- Nearly all of the health impacts are more frequently reported by high burden caregivers than those who have a lower burden of care.
- Caregivers who live in a rural area or a small town are more apt to experience depression as a result of caregiving (68%) than are urban or suburban caregivers (59%).

- Lower income caregivers, those with less than \$50,000 in household income, are more likely than higher income caregivers to gravitate to poor eating habits because of caregiving (61% vs. 48%).
- Many negative health effects are more common when the veteran has TBI, PTSD, or a mental health condition such as depression or anxiety.

Every time I made an appointment with my own doctor, something would happen to him, so I would cancel that appointment and deal with him. I realized that I hadn't taken care of myself at all, so I needed some time to do that.—Interviewee #18

I've gained weight, because I am not spending nearly as much time taking care of myself as I probably should...I feel like I've aged just from all the stress of dealing with it.—Interviewee #6

Figure 28:
Percentage Reporting Each Health Impact, by Veteran's Condition

	Mental Health Condition	No Mental Health Condition	PTSD	No PTSD	TBI	No TBI
Increased stress or anxiety	91%	81%				
Sleep deprivation	82%	66%	81%	72%		
Less time exercising	72%	63%			78%	66%
Weight gain or loss	70%	55%	69%	60%	76%	62%
Depression	72%	42%	68%	55%		
Delaying or skipping own doctor/dentist appointments	62%	49%			67%	54%
Poor eating habits	62%	40%	62%	47%	68%	51%
Generally getting sick more often	31%	17%	32%	18%	37%	22%

Qualitative Findings

Caregiving activities take time that caregivers would otherwise use to take care of themselves. They have less time for their own medical appointments, for exercise, or for grocery shopping and cooking healthy meals; they opt too often for fast food instead.

I worry about my health because I have no time to go to the doctor.—Focus Group 1

I got a prescription for glasses three weeks ago, and I have been so busy shuttling medicines over to him and all the stuff like that, that I never got the glasses. There is no time to take care of yourself.—Focus Group 1

A number say the stress of caregiving takes a toll on them, in some cases, leading to hypertension, more frequent illness, or depression.

They count on you 24 hours a day, so you are never able to relax because you are always worried about them.—Focus Group 6

You cannot spend your whole life taking care of somebody else. You have to have time for yourself. You will lose it. You'll snap.—Focus Group 5

I got depression, anxiety, stress and ongoing treatment. I'm taking medication, and it has helped. I'm rebounding. I took a dive right at first.—Focus Group 6

The added responsibility of providing care eats into caregivers' time for sleep. Those who provide round-the-clock care might have to provide care in intervals throughout the night, or might be awakened several times a night.

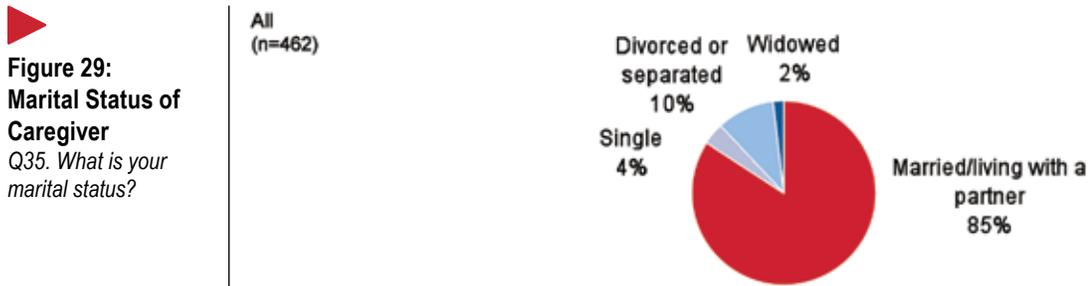
Is there any support out there so I don't have to get up every 2 ½ hours?—Focus Group 1

I miss being able to sleep through the night. If he does not take his nightmare medication, I am not sleeping.—Focus Group 6

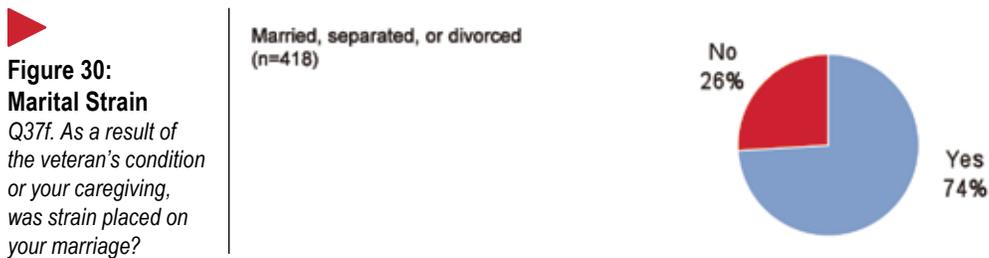
You walk around like a zombie most of the time. You're in total fatigue.—Focus Group 3

Impact on Caregiver's Marriage

A large majority of caregivers of veterans are married or living with a partner (85%).



Of those who are married, separated, or divorced, three-quarters say caregiving placed strain on their marriage (74%).



- Of those caring for their own spouse, eight in ten note the strain (79%), compared to only about six in ten (59%) of those who care for a veteran of some other relationship.
- PTSD is strongly associated with this marital strain (81% report it vs. 63% if no PTSD is present), as is depression/anxiety (79% vs. 60%) and, to a lesser degree, TBI (81% vs. 70%). By contrast, conditions such as diabetes and paralysis do not appear to make marital strain even more common among caregivers of veterans than it already is.

Qualitative Findings

Spousal caregivers or those who take care of their parents feel they become like a parent to the veteran. Spousal caregivers also say the “best friends” aspect of their relationship has dissipated, and now they cannot separate the patient from the spouse.

You become like a second mom, and he’s 24 and doesn’t want to be mommed. He wants to do his own thing. You don’t want to sit there and say, “Honey, you can’t go get groceries because you might freak out.” So the relationship is not best friends anymore. It’s like a job. I hate to say that, but I think he feels that. He feels like it’s not the same.—Focus Group 6

Spousal caregivers say physical intimacy diminishes. In some cases, it is because the veteran’s injury or medications make physical intimacy painful or unsatisfying. When this has happened, wives recount feeling unattractive, abnormal, and angry, although some are able to accept the loss of this part of their relationship.

A therapist recommended trying depression medication...One of the side effects is loss of libido. So he is starting to be a little bit more positive, but he has no interest in any sort of intimacy...I love him and want the very best for him, but it is just weird to try to help someone so much, and it seems like they are not even attracted to you...I feel insecure. I think what is it about me...like if I lose 5 pounds, if I do my hair better, if I do this it will make a difference. But I know it won’t.—Interviewee #8

Impact of Caregiving on Children

Three in ten caregivers of veterans have children under the age of 18 living in their home.

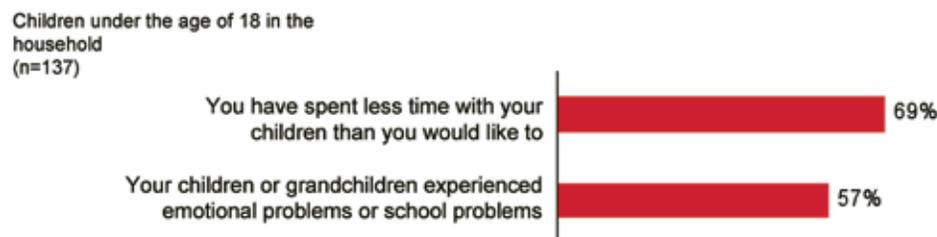
Figure 31: Children in the Household
Q36. Do you have any children under the age of 18 living in your home?



- Among those caring for a veteran under the age of 45, six in ten report the presence of children in the household (60%). This percentage declines to 24% when the veteran is 45 to 64 years old, and to 9% for older veterans.
- Depression/anxiety is particularly prevalent in the situations where children are present (80% of caregivers with children in the household say the veteran suffers from such a condition vs. 66% of others). PTSD is also more common in caregiving situations with children in the home (77% vs. 53% without children), as is TBI (47% vs. 22%).

Among the caregivers who have children in their household, seven in ten have sacrificed the amount of time they spend with their children (69%). More than half say their children have had emotional or school problems (57%).

Figure 32: Impacts of Caregiving on Children
Q37. As a result of the veteran's condition or your caregiving, has the following occurred?



- Emotional and school problems are more common when the veteran has TBI (67% vs. 48% with no TBI) or depression/anxiety (62% vs. 36%).

Qualitative Findings

Caregivers are very concerned about how their children are affected by the caregiving situation.

It's really affected our son tremendously...he's been depressed and had severe anxiety...there needs to be a resource that we can be able to reach out to other people, especially for the kids so that they understand that they're not alone...I've heard my kids say several times, "Nobody else gets it. Nobody else understands what I'm going through, especially at school."—Interviewee #26

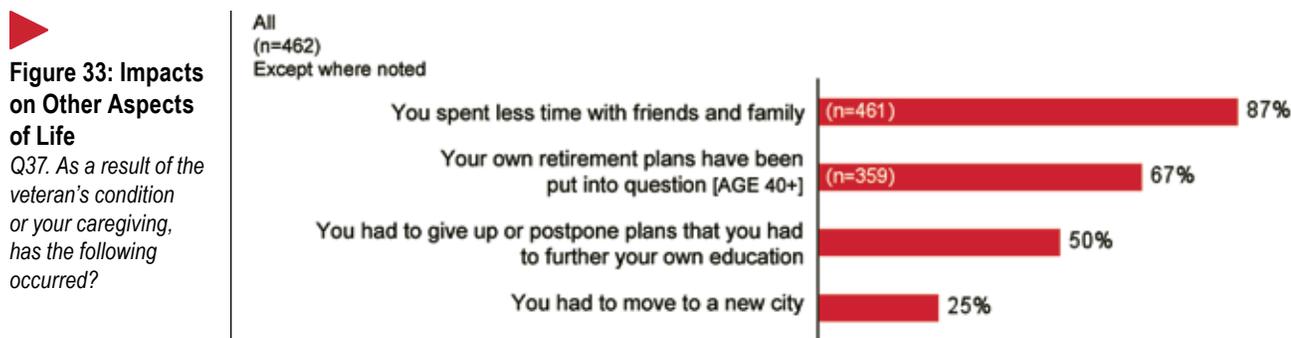
I have less time for them and everything is focused around Daddy...sometimes I have to send them away, and that is hard for them...there have been times when it has not been safe for them to be home.—Interviewee #25

Children can become caregivers themselves, even at a very young age.

They've become caregivers themselves. They will go down to their brother's room and check on him...if we go to the grocery store, usually one of them will go with me and they will walk around with Nate. If he's here, "Do you need this or do you need that?" They just keep a good eye on him, I guess is the way to put it. They notice the changes quickly. Like if he is in the bathroom too long, "Mom, do you think he's okay?" And we all sit there like we are on pins and needles waiting for him to walk out of the bathroom.—Interviewee #22

Impact of Caregiving on Other Aspects of Caregiver's Life

The impact of the veteran's condition and of providing care manifests itself in many other areas of the caregivers' lives, including their social life, family life, education, and retirement. The most widespread impact is a decrease in time spent with family and friends (87%).



- The proportion of caregivers reporting this decline in time with family and friends rises from 75% among low burden caregivers to 91% of high burden caregivers.

Two-thirds of those ages 40 or older say their own retirement plans have been put in question as a result of the veteran's condition or caregiving (67%).

- A larger proportion of high burden caregivers note this impact (72% vs. 58% of medium to low burden caregivers).
- Caregivers in households with less than \$50,000 in income are also disproportionately impacted in this way (73% vs. 61% of higher income households).

Half of caregivers of veterans (50%) claim that they had to give up or postpone their plans to further their education as a result of the veteran's condition or becoming a caregiver.

- This impact is more frequently reported by caregivers whose veteran has PTSD (55% vs. 43% no PTSD), TBI (60% vs. 46%), or depression/anxiety (54% vs. 40%).

Qualitative Findings

There are several reasons why caregivers see family and friends less often than they did prior to becoming a caregiver.

- Some find they cannot relate as well to people whose lives have taken a more typical path. Likewise, friends may be less comfortable coming to visit.
- They may be less interested in seeing friends if the conversation focuses mainly on the veteran's condition.
- Going out or taking a vacation requires more planning, to gather medications and equipment to accommodate the veteran's needs (e.g., a special toilet seat, bathing devices). Sometimes it is out of the question, so caregivers only see family when the family members are willing to do the traveling.
- If the veteran has PTSD, social outings may need to be limited because the veteran cannot tolerate a great deal of noise or various other environmental triggers.

I don't have a life. After like 6:00 I'm so tired, I just go shut myself in my room...there is no break. I don't have a lot of friends anymore; I don't go out anymore. This is it...I have no time for anything.—Focus Group 6

It takes too much energy to leave the house, too much preparation...my husband is incontinent, so you have to take his Pull-Ups, his wipes, the bag, gloves, change of clothes, water...then you have the wheelchair, the walker. If you're going somewhere for any length of time to a hotel, you have to take the toilet seat, you have to take something to bathe him, you have to take your whole house with you.—Focus Group 3

Caregivers are scared when they think about retirement, since caregiving has interrupted their earning and saving.

I am scared to death. I don't have any children. I have no idea who is going to take care of me...I think I need to put away a whole lot more money than I ever imagined I would need. Unfortunately, I did lose my job last year after I took family medical leave. Once I do get back to working...I think every penny I have will get put aside in savings...I am very, very concerned... Since I am just about 50, I hope I still have time to plan for my late, old age.—Interviewee #44

Retirement is scary because you don't even know if that's even possible anymore.—Interviewee #19

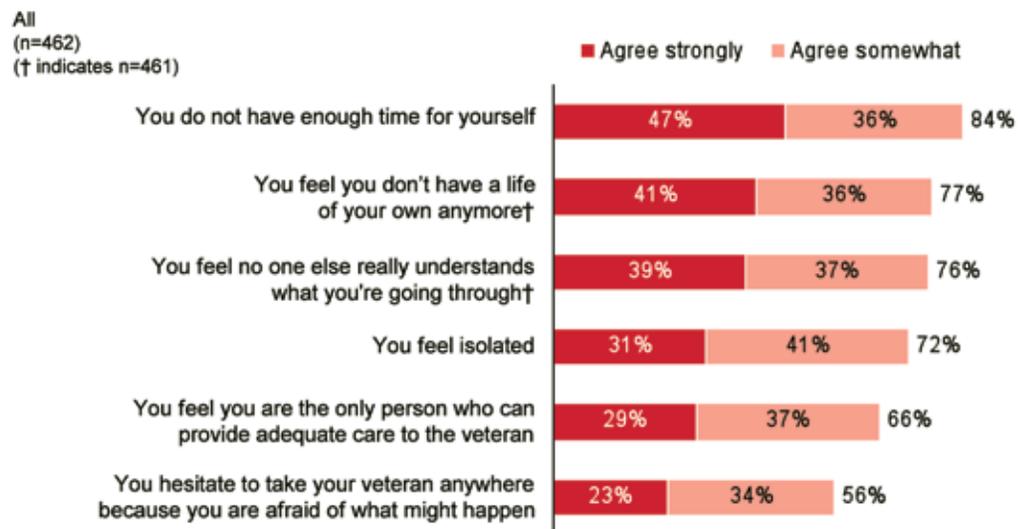
Additional Social and Emotional Impacts of Caregiving

One of the ways in which providing care to a veteran affects caregivers is that they no longer have enough time for themselves (84%). This may be why three-quarters (77%) feel they do not have a life of their own anymore.

- Caregivers of veterans who have a high burden of care are more likely to agree with these two beliefs, as well as all of the others shown in the graphic below.

My day revolves around his care...I have lost contact with some friends. There are certain hobbies that I like to do that I don't have time for. I have grandchildren who live in Georgia, and it is difficult for me to go see them. I don't feel like I have any "me time"...I don't feel like I'm an individual.—Interviewee #6

Figure 34:
Emotional Impact of Caregiving
 Q38. Please indicate how much you agree or disagree with each statement.



Three in four caregivers of veterans feel that others do not understand what they are going through (76%).

The friends and family that I had before the incident don't understand...his mom said to me recently, "He's not in the hospital anymore. I don't understand what's so difficult for you guys. He's all better, right? If he was sick, they would have kept him in the hospital." Uh-huh, yeah...I barely have the energy to keep my family afloat as it is. I do not have the energy to have to convince you that your son is damaged beyond repair.—Interviewee #14

- Those who care for a veteran with PTSD are more likely to feel this way (81% vs. 69% with no PTSD), and the same holds true for TBI (86% vs. 72%).
- Caregivers of younger veterans are also more likely to say that others do not understand their situation (<45: 87%, 45-64: 75%, 65+: 68%), even when controlling for the presence of PTSD and TBI.
- Interestingly, caregivers with no more than a high school diploma are more likely to feel this way (89%) relative to their counterparts with some college or technical school (78%) or college graduates (71%).

A significant majority of caregivers of veterans also feel isolated (72%), perhaps because of the perceived lack of understanding by others and the decrease in time spent with friends and family. More than half (56%) hesitate to take the veteran anywhere because they are afraid of what might happen, a feeling that can compound one's sense of isolation.

- Caregivers of veterans who have PTSD or depression/anxiety are more likely than their counterparts to feel isolated and hesitant to take the veteran out.

- Caregivers of younger veterans are also more likely to feel isolated, even when controlling for the presence or absence of PTSD and depression/anxiety.

One of the things that happens is I just don't think people know how to react to you. They don't know what to say, so they don't call. They don't come around. That makes it difficult...you feel like you're abandoned.—Interviewee #13

I realized that I had started isolating myself...I had to address my own behavior and put everything down at a certain point and say, "I have done everything I can do for today, and I'm taking an hour to just go for a walk around the neighborhood and chat and visit people"...it restores my capacity to go back into battle for him when I need to again.—Interviewee #24

Two-thirds of caregivers (66%) feel they are the only person who can provide adequate care to the veteran. This is not necessarily a negative outcome, however; it is positively correlated with the belief that caregiving is fulfilling, as well as the belief that gaining new knowledge and skills from caregiving is rewarding.

- The perception of being the only person who can provide care is reported more frequently by those who have been caregivers for three years or more (69%) than it is by those who have provided care for two years or less (57%).
- College graduates are less likely than others to think they are the only person who can provide adequate care (59% vs. 71% of those with lower education levels).

Positive Outcomes of Caregiving

The experience of caregiving engenders not just the social and emotional challenges described above, but positive feelings for many caregivers as well. Specifically, nine in ten (94%) feel proud of the support they provide, three-quarters (78%) feel a sense of reward from having gained new knowledge and skills from caregiving, and two-thirds (67%) convey that caregiving is fulfilling for them.

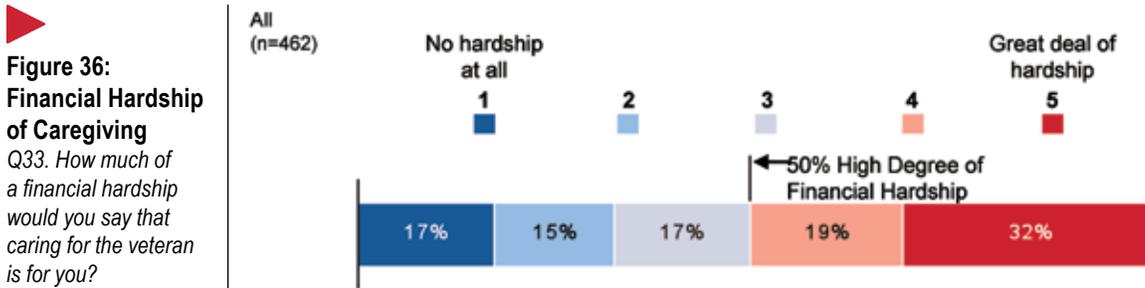


- Caregivers of veterans who are in households with less than \$50,000 in annual income are more likely than higher income caregivers to report that the experience has been fulfilling for them (71% vs. 60%).

I know I did an extremely good job with my dad, finding out what all the medical conditions were. I figured out how to pull him back from dialysis by changing his diet in a way that they didn't tell me to do, but it worked. Just being able to give him total respect and autonomy and, at the same time, propping him up from every side and doing that with grace. I am just really proud of doing that and doing it well.—Interviewee #15

Financial Hardship of Caregiving

Half of all caregivers of veterans surveyed (50%) report that caring for their veteran causes them a high degree of financial hardship (a rating of 4 to 5 on a 5-point scale). Nationwide, family caregivers are far less likely to report this level of financial hardship (13%).

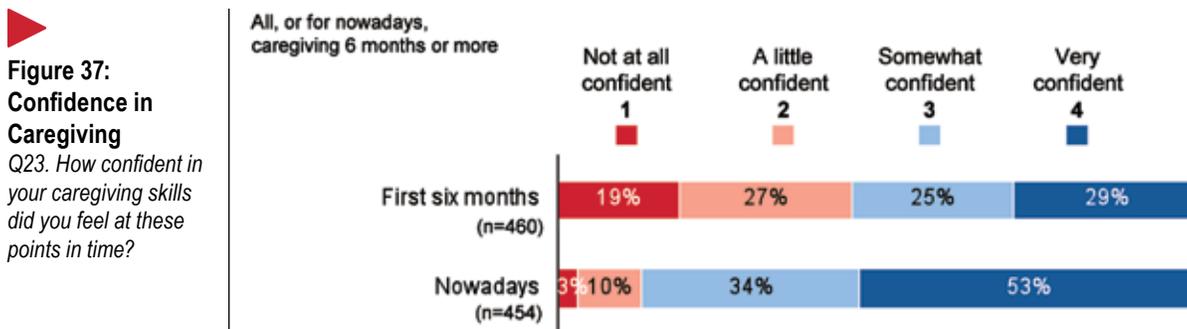


- As one would expect, a larger share of lower income caregivers report financial hardship of at least 4 on the 5-point scale (61% of those with less than \$50,000 in household income) relative to caregivers with more than \$50,000 in income (41%).
- Several conditions that the veteran may have are also associated with greater financial hardship:
 - PTSD (58% vs. 39% rating financial hardship 4 or 5)
 - TBI (58% vs. 47%)
 - Mental health conditions such as depression or anxiety (58% vs. 33%)

F. Caregiving Challenges and Needs

Confidence in Caregiving

Only about half of the caregivers say that they felt at least *somewhat* confident in their caregiving skills in the first six months of taking on this responsibility (54%). These results point to the importance of providing caregiving information, resources, and training in a person's early days as a caregiver. The proportion feeling at least *somewhat* confident "nowadays" increases to nearly nine out of ten (87%), including 53% who say they are *very* confident.



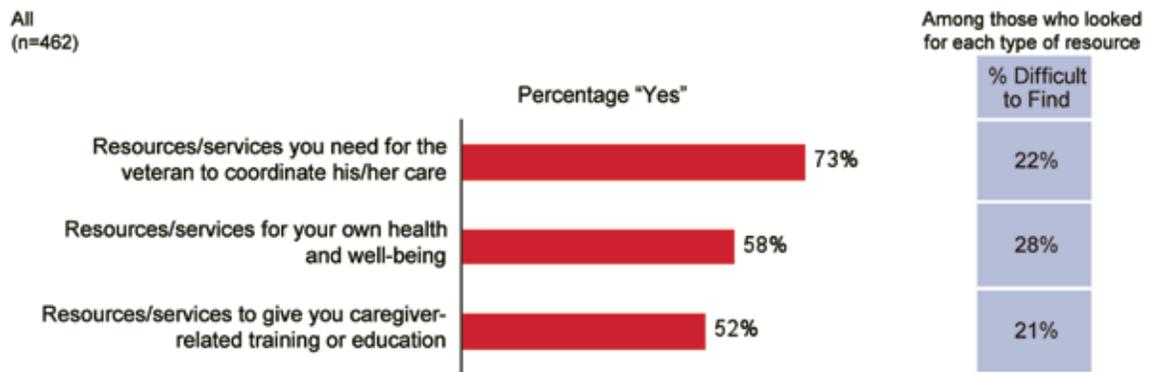
- Three subgroups of caregivers are more likely than their counterparts to say they lacked confidence in their first six months of caregiving:
 - Those providing care to someone with PTSD (51% vs. 39% non-PTSD *a little* or *not at all* confident)
 - Those with household incomes under \$50,000 (52% vs. 39% of higher income caregivers)
 - Caregivers with a high burden of care (50% vs. 37% of low burden caregivers)
- On the other hand, caregivers providing care to a veteran with diabetes are more likely than those whose veterans do not have this disease to feel *very/somewhat* confident (63% vs. 50%).
- Those who received information proactively from the Department of Defense (DoD) or the VA are also more apt to feel *very* or *somewhat* confident in the first six months (66% vs. 49%).
- Although these differences between subgroups of caregivers diminish over time, caregivers of veterans with PTSD remain more likely than others to say that they lack confidence nowadays (16% vs. 9% *little* or *no* confidence).

Seven out of ten caregivers of veterans say they have sought out resources/services they need to coordinate the veteran's care (73%), and six in ten have looked for resources for their own health and well-being (58%). About half sought out caregiver-related training or education (52%).

Most caregivers appear to find what they are seeking, since only about one in five of those who sought resources to coordinate the veteran’s care or who sought caregiver education says these were difficult to find. The type of services or resources that are the most difficult to find are those that support the caregiver’s own health and well-being; 28% say this was *very* or *somewhat* difficult.

Figure 38: Finding Resources

Q24. Have you looked for the following resources that may be available to you or the veteran from any community or governmental organizations?
Q25. If yes, how easy or difficult were they to find?



- An inclination to look for all three types of resources and services is noticeably higher among caregivers who have education beyond high school. This may mean that information dissemination efforts will require greater outreach for caregivers with less education.
- A larger share of caregivers whose veteran has depression/anxiety seeks resources to coordinate the veteran’s care (77%) than caregivers of veterans without this condition (64%).
- Among those who have sought these types of resources, caregivers of veterans with PTSD and TBI are less likely than those whose veterans do not have these conditions to experience difficulty finding them.

Figure 39: Percentage Very/Somewhat Difficult to Find Resources, by Veteran’s Condition

Resources or Services	PTSD	No PTSD	TBI	No TBI
To coordinate the veteran’s care	16%	32%		
For your own health and well-being	22%	37%	13%	35%
To give you caregiver-related training or education	17%	28%	12%	25%

- Caregivers of veterans age 65+ are more apt than caregivers of younger veterans to experience difficulty finding resources to help with their own well-being (37% vs. 23%).

Qualitative Findings

A number of caregivers who sought caregiving support groups using online search techniques and by making phone calls could not find groups that met their needs.

I couldn't find any caregiving support sites whatsoever...I was using Google, putting in every search term I could think of...caregivers, caregiver support, veteran support, helping injured people, injured veterans. Then just do-gooder stuff comes up under that: "We support the troops. Take 10% off."—Interviewee #5

I've found plenty of support groups for caring for your elderly parent, but no support groups in my area for spousal caregiving. That is a huge, huge need. There's an organization called Wellspouse, but there's nothing close to Tennessee.—Interviewee #11

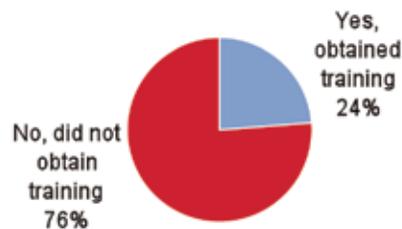
I found support groups for people who are suffering from PTSD, but not for caregivers of PTSD.—Focus Group 5

When asked if they have obtained any formal training for how to care for someone with their veteran's needs, only one-quarter of caregivers say they have (24%).

Figure 40: Caregiving Training

Q25d. Have you obtained any formal training about how to care for someone with your veteran's needs?

All
(n=462)



- As the caregiver's education level rises, so does the likelihood of attending formal caregiver training, from 15% of those with no more than a high school degree to 28% of college graduates.
- The caregivers who are in more time-intensive situations may be less able to set aside the time for training. Only 20% of those who spend more than 20 hours per week providing care have obtained formal caregiver training, whereas 31% of caregivers spending fewer hours per week have done so.
- Those caring for a veteran with TBI are less likely to have obtained training (15% have, compared to 27% of those whose veteran does not have TBI), even when controlling for the number of hours of care provided.
- Caregivers who come into their role at least several months after the veteran began needing care are more apt to obtain training than are those who began providing care from the start (30% vs. 21%).

Caregiving Challenges Faced

Of 11 possible caregiver challenges examined in the survey, the four top challenges experienced by caregivers of veterans are:

1. Not knowing what to expect medically with the veteran’s condition
2. Not being aware of VA services that could help
3. Not knowing how to address PTSD or mental health conditions (among those who report that such a condition is present)
4. Difficulty getting through bureaucracies in order to obtain services

At least eight in ten caregivers of veterans consider each of these a challenge, with roughly half saying these were *major* challenges.

Figure 41: Caregiving Challenges
 Q26. Have you personally experienced the following challenges at any point since you became a caregiver? If yes, to what degree?



- Lack of awareness of VA services and difficulty navigating bureaucracies are both more common among caregivers of veterans with PTSD, TBI, and depression/anxiety.
- Caregivers whose veterans were mobilized from the National Guard or reserves are also more likely than those who care for a veteran who was on active duty to be unaware of what the VA has to offer (96% vs. 86%). [Note: n=27 for reservists/Guard.]

The next most common challenges, each experienced by two-thirds of caregivers of veterans, are:

5. Not knowing where to obtain financial assistance

- Lack of knowledge of how to find financial assistance is more frequently reported by caregivers of veterans with PTSD (74% vs. 61% of others) and TBI (76% vs. 66%).

6. Not knowing where to turn to arrange a break from caregiving

- Caregivers whose veterans have TBI are more inclined than others to have this information need (75% vs. 65%).

7. Not knowing where to obtain specialized care

- This is more prevalent among caregivers of veterans with TBI than other caregivers (76% vs. 62%).
- The likelihood of experiencing this challenge is greater among caregivers whose veterans have one or more care managers than among those without a care manager (74% vs. 59%).

Roughly half of caregivers of veterans report encountering each of the remaining four challenges:

8. Not knowing how to pay for or arrange home modifications

- This increasingly becomes a challenge as the age of the veteran rises; 41% of those whose veterans are less than 45 years old note this challenge, compared to 66% of those caring for a veteran 65 years or older.
- Caregivers whose veterans have diabetes are more apt than others to have encountered this challenge (67% vs. 51%).

9. Feeling excluded from decisions about the veteran's care

- Caregivers who are the veteran's parent are more likely than spouses or other relatives or friends to feel excluded from decisions about the veteran's care (73% vs. 54%).
- Lower income caregivers are also more likely to feel excluded (64% with household income of less than \$50,000 vs. 49% of those with greater income).
- Those whose veterans have PTSD, TBI, or depression/anxiety are also more apt to report this challenge. They may feel more of a need to be involved if they believe the veteran's condition impairs his/her ability to communicate effectively or to direct his care independently.

10. Not knowing how best to plan transitions in and out of care facilities

- Caregivers whose veterans are 65 or older are more apt than younger caregivers to think planning for transitions is challenging (59% vs. 46% of those with younger veterans).

11. Not knowing how to properly administer medical treatments, care, or medications

Qualitative Findings

Not Knowing What to Expect

You don't see it when you look at my husband, but he is very, very ill. So I would like some training...I don't know what to expect from him. Is it reasonable to expect that he will be able to get up and find a job again? What can I expect with the next [recurrence of cancer]? What am I supposed to look for?—Focus Group 3

With a head injury, I think there should be more awareness for the risk of seizure, and training—what happens if there is a seizure? I knew that it was a possibility, but I didn't know what to do if it happened or what it would look like or what anything. [I learned later that] with my husband, it was a good possibility because he had a penetrating head injury...I was in the hospital room [during] his first seizure. It was 3:00 a.m., and I thought he was dying. I didn't know what was wrong with him. It was the most horrifying experience of my life. Someone told me along the way that I could put a Valium under his tongue and it would stop the seizure faster. I didn't know that.—Focus Group 2

In the beginning, he would have bouts of anger. Like one day, he came upstairs and he had had a flashback and he just punched the wall. I had to learn to reach him. [Not knowing what to expect] was scary, it was lonely, it was confusing.—Interviewee #45

Not Being Aware of Services of the VA

That's hard for me, navigating through the VA system...There is no how-to book on how to do it...who do I call?—Focus Group 3

When he came home...we did not know the resources that were available. He just jumped right into any job, which unfortunately is in a mortuary. So that didn't help his PTSD. We didn't know what we could do. We didn't know he could get on disability...we didn't know how to get into the VA system, how to navigate that. Getting a case worker; where do we go for that? Which hospital does he go to? It's just we didn't know if there were options for us.—Focus Group 6

Not Knowing How to Address PTSD or Mental Health Conditions

It was easy to find some stuff on PTSD, but there is not really much to find about how the family can be helped with it.—Interviewee #16

It's very confusing when you don't understand what is happening, such as a violent outburst or a crying episode. Most of what we found out we discovered by doing research. We looked at his discharge paperwork and saw that he had PTSD. So we did a Google search on PTSD and read what some of the signs and symptoms and triggers were, and that is how we got a lot of the information.—Interviewee #6

Difficulty Getting Through Bureaucracies

The best way to describe it would be that you know something is attainable. You know that a program is out there, but you're in a maze. You just can't figure out how to get there and at every turn somebody says no...I would call the VA locally, and they wouldn't know anything about it. They would tell me that I must be wrong because that doesn't exist. I would quote the regulation that it exists under, and they would say, "I have to look into it," and then you wouldn't hear from them for six months.—Caregiver #29

If you are 100% disabled, you are supposed to get some sort of handicap parking placard...so he goes to the DMV and fills out the paperwork, and they tell him that they don't know what he is talking about...they send him away with a paper to the VA. So he brings that paper to the VA, and the VA doctors say, "We don't know what you are talking about. We have never seen this paper." So those are the cases when I just have to get involved...and take that stress off of him.—Caregiver #8

We were told by the VA and the fiduciary that my daughter's phone cannot be on our cell phone plan because she is over 21. I keep telling them that this is for medical purposes, because she is the other caregiver in the home to take care of my husband. Red tape. "No, you either take her off or we're going to cut your telephone service off and give you prepaid phones." Nobody is trying to cheat the government. We're trying to take care of a man in this house.—Interviewee #21

Not Knowing Where to Find Financial Assistance

At the beginning, before any of her money came in from the government, her retirement, her disability, we were without income...we became very deep in debt to the point where we had to file bankruptcy. I wasn't [able to find someone to direct me to sources of financial assistance]...I really just didn't know who to ask because I know it's there.—Interviewee #36

Not Knowing Where to Obtain Specialized Care

I live in a very large town. You would think there would be tremendous resources available, but it's difficult to figure that kind of stuff out. Who do you go to? For example, when he was experiencing the hallucination about the soldiers and the police...I took him to the local Army hospital...there was nothing physically wrong, so they said, "Well, we can't keep him. We don't have a psychiatric unit. Try the Air Force hospital across town." Over there they said, "Well, we do have a psychiatric unit, but it's only for active duty."—Interviewee #13

Feeling Excluded from Care Decisions

You get an 800 number to call, and even though I have been given authority by Richard and it's in the VA file, they had no idea where to find authorization so they could talk with me about him and some of these things I was chasing after.—Interviewee #12

There were a couple of times when they just decided to do something, and here I am under power of attorney and they didn't tell me. They just went ahead and did it.—Interviewee #38

Not Knowing How to Plan for Transitions

You get there and...they know whether it's going to be three months or four months, but they wait until the last 24 hours to start going through “here's what the out-processing is,” and “You need a special bed and you're going to need this”...[I wish they had] trained me throughout the process instead of waiting.—Focus Group 4

I'm being told my son is being discharged in a couple of days and we don't have anywhere to live, and nobody helped me find a place to live...I sat in the hospital with him in his room, me in the anteroom whispering, and I must have called 200 general apartment complexes. “Do you have a first floor apartment with a shower stall not a tub?” You don't even want to know what we're spending in rent because nobody helped me find a place.—Focus Group 4

Not Knowing How to Administer Therapies and Treatments

My biggest fear was they just dumped all of these medications in my lap... it makes me so nervous dishing out all these medications...that I could hurt him, that he could have some type of reaction to the medication, that I could make an error in the medication.—Focus Group 1

One of the hardest things...is giving him his shots. I had heard somewhere that it's like an orange. I went in the kitchen and I found the orange. Even now...I haven't been taught how to do it properly.—Focus Group 3

Ease of Finding Caregiving Help

Caregivers of veterans were asked, if they ever needed a break, how difficult it would be to find someone to take on their caregiving responsibilities. Three-quarters (74%) respond that this would be difficult for them, including 48% who say it would be very difficult.

Figure 42: Ease of Taking a Break

Q28. If you ever felt you needed to take a break from your caregiving, how easy or difficult would it be for you to get someone else to take on your caregiving responsibilities?

All
(n=462)



- As burden of care rises, so does the difficulty of finding someone to give the caregiver a break. Among caregivers with a low burden of care, half (51%) report it is *very* or *somewhat* difficult to find someone to take on their responsibilities, whereas 83% of high burden caregivers say this is the case.
- Caregivers whose veterans have PTSD, TBI, or depression/anxiety have greater difficulty finding someone to give them time off. Roughly half of each of these groups say it is *very* difficult, compared to about four in ten of their counterparts.

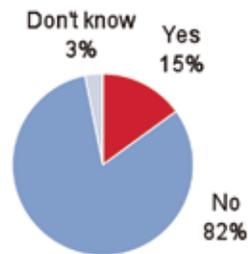
Use of Respite Services

The large majority (82%) of caregivers indicate they have not received any respite services from the VA or any other organization in the past year. Only 15% say they have received some sort of respite services from an organization.

Figure 43: Respite Services

Q19c. In the past 12 months have you received any respite services from the VA or any other organization?

All
(n=462)



- High burden caregivers are far more likely to receive respite (19%) relative to those with a medium burden (10%) or a low burden of care (3%).
- Caregivers of older veterans—those at least 65 years of age—are nearly twice as likely as those providing care to a younger veteran to have used respite services (20% vs. 12%), but this difference is driven by the higher burden of care shouldered by caregivers of older veterans.
- Caregivers whose veterans have PTSD are only about half as likely as other caregivers to have received respite services (11% vs. 20%).
- The likelihood of receiving respite services rises in relation to the number of care managers, from 10% of those whose veterans have no care manager to 23% of those with two or more.

G. Information Sources

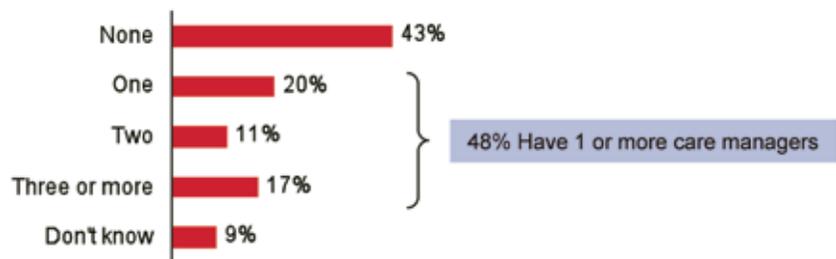
Presence of Care Manager

Four in ten caregivers indicate that the veteran they care for has no professional case manager, care manager, or social worker coordinating his/her care and assistance. One in five says the veteran has one such person working with them (20%), and three in ten say there are two or more people in this position (28%). Even though care managers are supposed to be a single point for coordinating care, 17% of caregivers say the veteran has three or more care managers.

Figure 44: Number of Professional Care/Case Managers

Q20. How many professional case/care managers or social workers does the veteran have, if any, coordinating his/her care and assistance? (Do not count yourself)

All
(n=462)



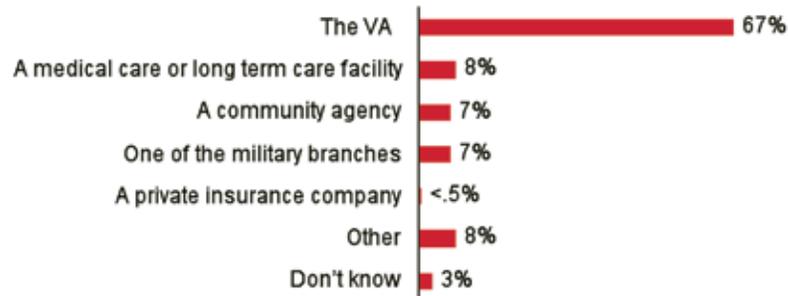
- Those who live in a small town or rural area are more likely than those in urban or suburban areas to report there is no care manager at all (49% vs. 38%).

Among those caregivers whose veterans have one or more care managers, most (67%) say that the care manager who has spent the most time helping them works for the VA.

Figure 45: Case/Care Manager Organization

Q21. Within what organization is the care/care manager or social worker employed?
[IF MORE THAN ONE CARE MANAGER]
Please think of the one care manager or social worker who has spent the most time helping with the veteran's case.

Veteran has one or more case managers
(n=221)

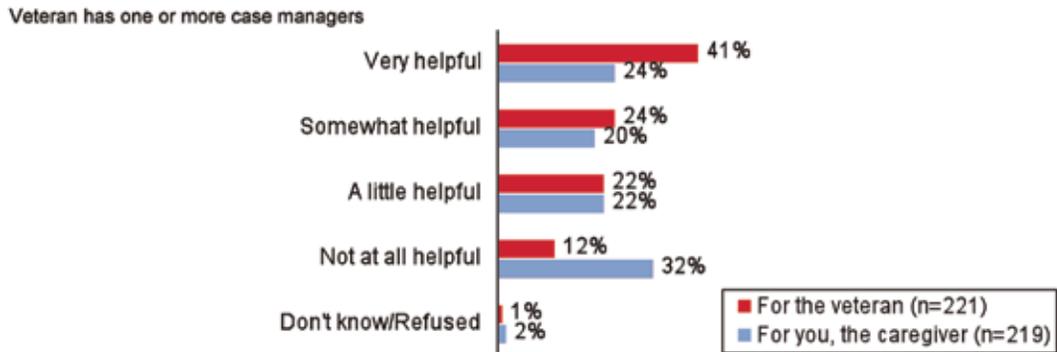


Helpfulness of Care Manager

Two-thirds of caregivers whose veterans have a care manager say s/he has been at least *somewhat* helpful in locating, arranging, and coordinating care and resources for the veteran, including 41% who say the care manager has been very helpful. As to finding resources for the caregivers themselves, the care managers are given lower ratings of helpfulness. Only four in ten caregivers say the care manager has been even *somewhat* helpful in finding resources for them as caregivers (43%), and one-third go so far as to say that the care managers have not been helpful at all in this regard (32%).

Figure 46:
Case/Care Worker
Helpfulness

Q22. How helpful has the care/case manager or social worker been in locating, arranging, and coordinating suitable care and resources...



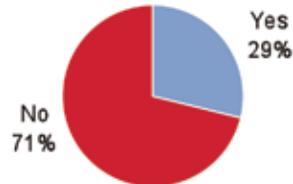
- The caregivers who have two or more care managers are more apt to say the principal care manager is *very* or *somewhat* helpful in addressing the veteran’s needs (73%) than are those with just one care manager (54%).
- Caregivers of veterans with PTSD are *less* likely than those whose veterans do not have this condition to rate the care manager as helpful for the veteran (59% vs. 75%).
- Caregivers with a high school degree or less education are more likely than those with greater education to rate the care manager as *very* helpful in locating and coordinating resources for the veteran (64% vs. 37%). The same holds true for caregivers of veterans age 65 or older (51% vs. 36% of those with younger veterans).

Proactive Information

Most caregivers (71%) say the VA and DoD military systems have not *proactively* given them information or links to information to help them understand the veteran's condition, treatment, or services.

**Figure 47:
Proactive
Information**
Q27. Did anyone within the VA system or the DoD military system proactively give you information (or links to information) to help you understand the veteran's condition, treatment, or services?

All
(n=462)



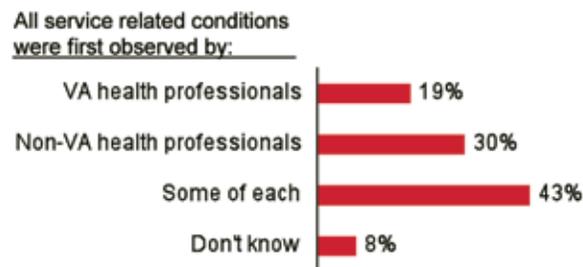
- Caregivers whose veteran has a care manager are twice as likely as those without a care manager to report receiving information proactively (39% vs. 19%).

Health Providers

Whichever health providers first observe veterans' service-related conditions are in a good position to give information to their caregivers about how to provide care for that condition and where to find helpful resources. Three in ten caregivers of veterans report that once the veteran was no longer on active duty, all of his/her service-related conditions were first observed by non-VA health professionals (30%). Another 19% say the veteran's conditions were first evaluated by VA health professionals, and 43% say both the VA and non-VA providers were first on the scene for certain conditions.

**Figure 48:
First Health
Professionals
Seen**
Q9a. Who were the FIRST to observe his/her service-related conditions once he/she was no longer in the military?

All
(n=462)



Qualitative Findings

Those who say some of their veteran's conditions were first observed by a non-VA professional include those where new symptoms or conditions emerged well after leaving military service—such as PTSD or illnesses related to Agent Orange. In those cases, non-VA health providers have the opportunity to be important sources of information and resources to the caregiver. Of course, it is also critical that these providers know what conditions are service-related so that they can refer the veteran to the VA for treatment and benefits.

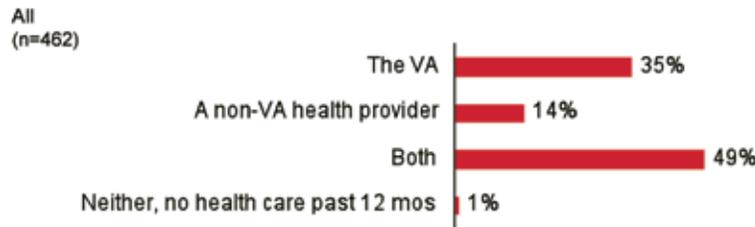
Interviews with caregivers reveal, however, that many of those who reported that non-VA health professionals first saw certain conditions were thinking about the military or TRICARE health professionals who saw their loved one before s/he had even separated from service.

Our civilian therapist is the person who noticed his PTSD first. She told him that he needed to be seen by military mental health.—Caregiver #25

Half of all caregivers (49%) say the veteran has received care from both the VA and non-VA health providers in the past 12 months. More than one-third of caregivers indicate solely the VA as the veteran's health provider (35%) and one in seven indicates only non-VA providers (14%).

Figure 49: Health Providers of the Past 12 Months

Q9b. Within the past 12 months, through what provider(s) has the veteran received health care?



Usage and Helpfulness of Information Sources

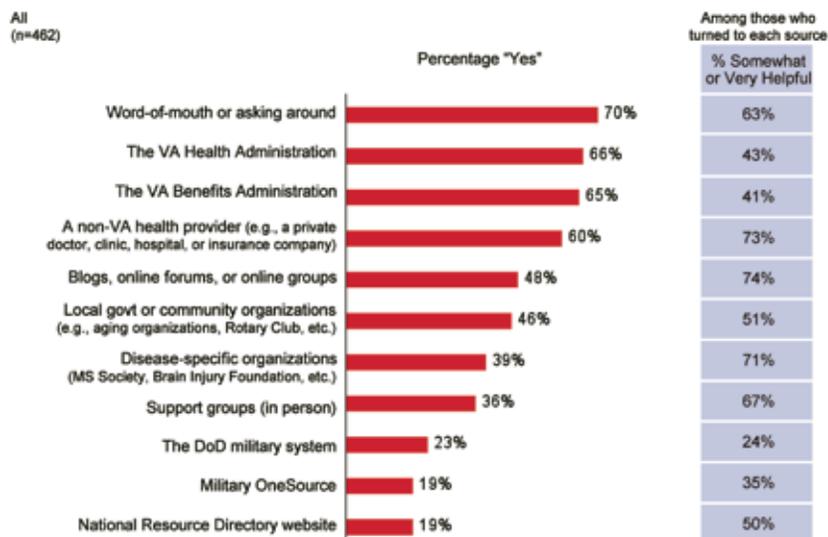
Word of mouth is the most popular information channel used by caregivers (70%), and six in ten of those who used it found it to be *somewhat* or *very* helpful (63%). The VA Health Administration and Benefits Administration are also popular sources of information—two out of three caregivers turn to each (66% and 65%, respectively). About four in ten of those who turned to these VA sources found them helpful (43% and 41%, respectively).

The sources of information that garner the highest proportions of “helpful” ratings by the caregivers who use them are:

- Blogs, online forums, or online groups (74% helpful)
- Non-VA health providers (73%)
- Disease-specific organizations (71%)
- In-person support groups (67%)

Figure 50: Sources of Information

Q29. Did you turn to any of the following avenues to look for caregiver resources and information?
Q30. If yes, how helpful was this source?



Detailed Findings

- In general, the likelihood of turning to any of these sources of information rises with education level, with the exception of the VA Benefits Administration and Military OneSource (a website).
- The usage of information sources varies by geographic location, with urban and suburban caregivers more likely than rural or small town caregivers to turn to support groups (41% vs. 30%) and local government and community organizations (52% vs. 40%).
- Caregivers taking care of younger veterans are more likely than those taking care of older ones to turn to online forums, the DoD military system, and Military OneSource, but the reverse is true for local government and community organizations.

 **Figure 51:**
Percentage
Turning to Each
Source, by Age of
Veteran

	Age of Veteran		
	Less than 45	45 to 64	65+
Blogs, online forums, online groups	62%	48%	35%
DoD military system	43%	16%	11%
Military OneSource	42%	13%	6%
Local government or community organizations	41%	41%	54%

- The online groups and Military OneSource are also more commonly used by those caring for a veteran with PTSD, TBI, or depression/anxiety, even when controlling for the veteran's age.
- Caregivers who took on their role in the first few months that the veteran began needed care are more likely than those who became caregivers later on to say they turned to the VA Benefits Administration for information or resources (69% vs. 55%).
- Caregivers with no more than a high school degree who use certain sources of information (those in the table below) are more likely than those with greater education to consider them helpful.

 **Figure 52:**
Percentage Rating
Each Source Very/
Somewhat Helpful,
by Caregiver
Education

	High School or Less	Education Beyond High School
VA Benefits Administration	63%	38%
VA Health Administration	59%	41%
Disease-specific organization	100% (n=10)	69%
Local government or community organization	72% (n=18)	49%

- The two VA administrations are more highly rated by caregivers whose veteran has two or more care managers than by those whose veteran has just one or none. Specifically, half of those with two or more care managers who turned to the VA Health Administration (51%) or Benefits Administration (52%) consider them to have been helpful, compared to 38% and 33%, respectively, of caregivers whose veteran has fewer care managers.
- Caregivers dealing with situations involving PTSD who turned to the VA Health Administration are notably less likely to have found the administration helpful, relative to those whose veteran does not have PTSD (35% vs. 55%), and results are similar for caregivers dealing with TBI (29% vs. 48%) and depression/anxiety (39% vs. 53%).
- Those dealing with PTSD are also less likely to say the VA Benefits Administration was helpful (32% vs. 56% without PTSD). However, caregivers whose veteran is paralyzed or has a spinal injury are more likely to say it was helpful (61% vs. 35%).
- Among those who used the DoD military system, caregivers who have been in their role for two years or less are twice as likely as longer-term caregivers to rate it as helpful (42% vs. 19%).

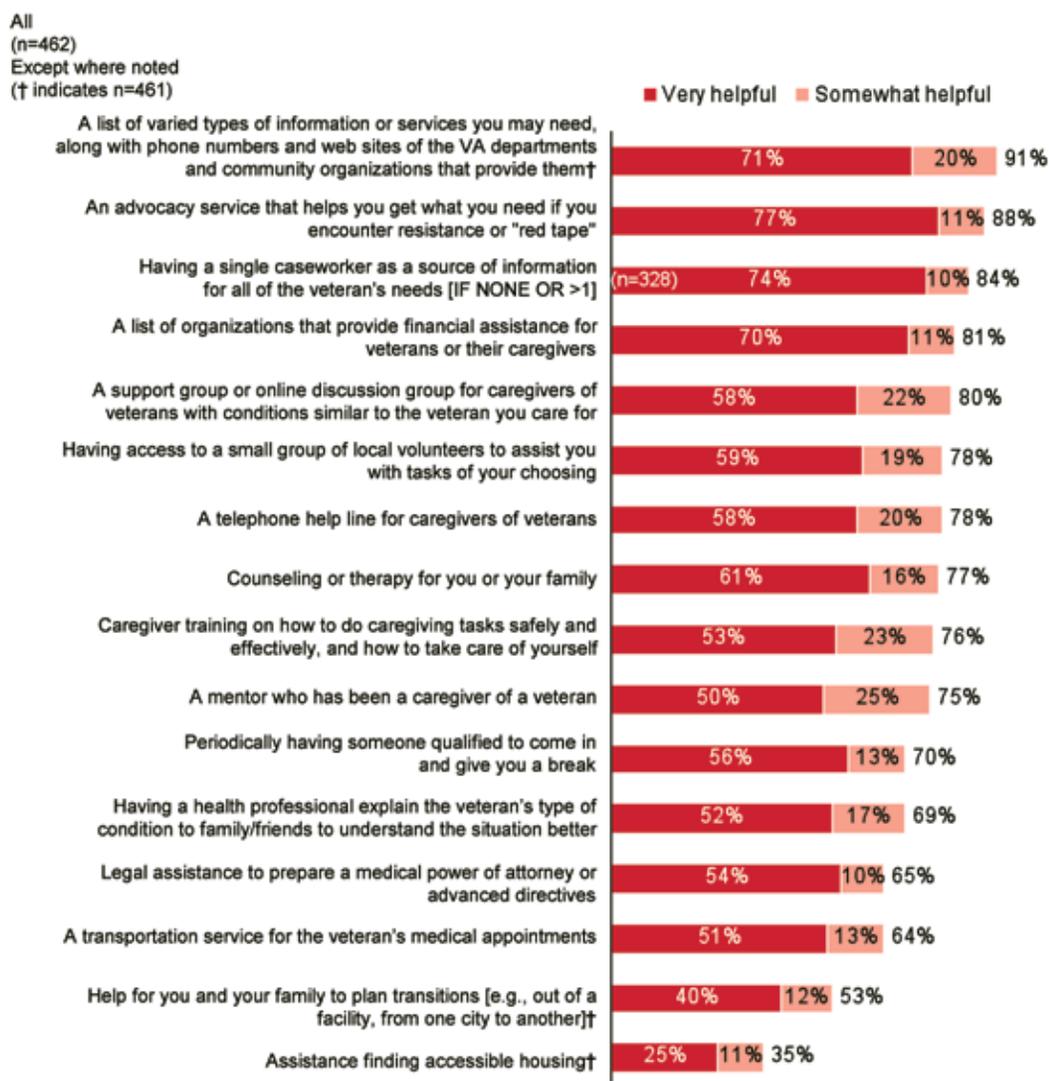
H. Helpfulness of Programs and Services

Helpfulness of 16 Selected Programs

Caregivers of veterans were asked how helpful each of 16 programs or services would be, or if they had already used such a program, how helpful it actually was. The list of programs was developed using input from caregivers of veterans who participated in focus groups, specifically to address the challenges they had faced. The programs appear to be on target, since all but one—assistance finding accessible housing—elicit ratings of *somewhat* or *very* helpful from a majority of caregivers. The proportions of caregivers who find each of these programs and services helpful reveal the relative level of need for each service. Four services stand out as *very* helpful to at least seven in ten caregivers:

1. A list of types of information/services available and contact numbers of organizations that provide them
2. An advocacy service
3. Having a *single* care manager (asked of those who did not have any care manager or who had more than one)
4. A list of organizations that provide financial assistance for veterans or their caregivers

Figure 53:
Helpfulness of Programs and Services
 Q42. How helpful would the following services have been to you, if at all, in addressing the needs, challenges, and difficulties you have already faced as a caregiver?



Several of the next tier of services—a support group, a telephone help line, and a peer mentor—provide both information and empathetic support to the caregiver. Each of these is rated as *somewhat/very* helpful by at least three-quarters of caregivers (80%, 78%, and 75%, respectively). Similarly, counseling or therapy for the caregiver or his/her family is also helpful to three-quarters (77%).

- Presence of a care manager seems to diminish caregivers' need for a telephone help line. Among caregivers whose veteran has no care manager, 84% think a telephone help line would be *very* or *somewhat* helpful, compared to 76% of those whose veteran has a care manager.
- Caregivers with veterans under the age of 45 are more apt to rate counseling as helpful (84%) compared to those with a veteran ages 45 to 64 (75%) or 65+ (73%).
- Perhaps related, the presence of several medical conditions is also related to receptivity to counseling: PTSD (81% vs. 71% with no PTSD), TBI (83% vs. 75%), and depression/anxiety (81% vs. 69%).
- Caregivers with at least some college are more likely than those with up to a high school degree to consider counseling helpful (80% vs. 61%).

Certain subgroups of caregivers appear to have a greater need for some of the remaining programs and services evaluated in the survey:

- Newer caregivers—those in their role for two years or less—are more receptive to having local volunteers organized to help them with tasks of their choosing (86%), and receptivity declines to 73% of caregivers who have provided care for five years or more.
- Perceived helpfulness of having a health professional explain the veteran's condition to family and friends so they can understand the situation better is more prevalent among caregivers of veterans with PTSD (74% vs. 62% without PTSD) and among caregivers of veterans with depression/anxiety (74% vs. 58%).
- Perceived helpfulness of having someone qualified come in to give the caregiver a break rises in relation to the veteran's age, from 60% of caregivers whose veteran is under the age of 45 to 78% of those with a veteran age 65 or older. It also rises in relation to the burden of care, from 48% of low burden caregivers to 78% of those with a high burden.



I. Respondent Profile

The caregivers who responded to this survey include four in ten with a bachelor's degree or higher education. Additionally, 44% have some college or trade/business school. Half have less than \$50,000 in household income.

They live in a varied mix of urban, suburban, small town, and rural locations. Most are non-minority whites, but a range of minorities are also represented.

 **Figure 54:**
Demographic
Profile of
Respondents

	Caregivers of Veterans
Education	(n=461)
Some high school or less	2%
High school graduate	11
Some college/trade or business school	44
Bachelor's degree	18
Post graduate work	7
Graduate school degree	18
Household Income	(n=462)
<i>Less than \$50,000 (net)</i>	49%
No income	3
Less than \$15,000	6
\$15,000 to \$29,999	14
\$30,000 to \$49,999	27
<i>\$50,000 or more (net)</i>	36
\$50,000 to \$74,999	21
\$75,000 to \$99,999	9
\$100,000 or more	6
Decline to answer	14
Caregiver Living Location	(n=462)
Urban	16%
Suburban area surrounding an urban area	35
Small town	25
Rural area	23
Don't know	2
Caregiver Race/Ethnicity (multiple responses allowed)	(n=461)
White, non-minority	82%
African American	9%
Hispanic	8%
Asian	4%
Native American	5%
Other minority	2%

Detailed Findings

There is a concentration of respondents who live in the South, although one in five lives in the West or Midwest. One in ten lives in the Northeast.

 **Figure 54:**
Demographic
Profile of
Respondents
(continued)

	Caregivers of Veterans
Region	(n=462)
South	50%
West	21
Midwest	19
Northeast	10
Outside of the U.S.	1



Recommendations

Knowing that caregivers of veterans tend to be in their role for a significantly longer period of time and have a heavier burden than caregivers nationally, it is even more important to give them information and support services as early as possible, to help reduce the long-term toll from caregiving.

During in-depth interviews, caregivers of veterans discussed how they would design programs and services to meet their needs, and how they personally would benefit from the programs they were describing. The programs and services recommended below were developed using their input. The programs would help them feel less stressed, help them regain their health, and help them regain balance in their lives. Just as important, caregivers tell us that these programs would also help them to be better, more effective in their caregiving role. Some programs would give them instrumental knowledge that they need to provide care, others would help them find and obtain services for the veteran, and still others would give them more psychological strength to bring to their continuing role as caregiver.

Vignettes of Selected Caregivers

Lisa

Lisa quit her job to care for her brain-injured son around the clock and says she is lucky if she gets two hours of sleep a night. She had to move to a warm weather climate for her son. She says, “We had to leave everybody, our family, our friends. I was a very social person. I was an empty nester. I was enjoying it.” Because of his brain injury, her son gets over stimulated very, very easily. So they sit in the house, he in his bedroom and she somewhere far from his room trying to be quiet. She says, “You can’t talk on the phone. I can hardly watch TV, no radio, nothing.” She is the sole caregiver, except for a small amount of help from her young adult daughter. She has no other family who can help with her son’s care, and is unaware of any home health care services.

Lisa says her son seems to know what is going on around him, almost everything, but he can’t verbalize much—he’s up to about a hundred words now. With no income, Lisa has relied on donations for her own living expenses. After two years of providing care, these donations are dwindling and she does not know what to do. She manages her son’s disability income, but feels she cannot even allow him to pay for her dinner at a restaurant. Lisa is upset that no one from the military has visited her son in the two years that she has been caring for him. Emotionally, the situation is tough on Lisa, who says, “You realize your life is over...don’t get me wrong, I’m happy my son is alive. I would take this over the alternative. But it still leaves me with absolutely no future to look forward to, nothing.”

1. Provide Training and Information for Common Veteran Conditions

The very high prevalence of depression/anxiety and PTSD among the veterans served by family caregivers means that these would be prime illness areas around which to build caregiver support resources. TBI and diabetes are also topics that could be targeted. If a complete set of resources were to be developed just for these four conditions, the lives of nearly nine in ten caregivers of veterans could be touched—88% report one or more of these conditions. In fact, 65% of caregivers report their veteran has at least two of these conditions. Helping caregivers who are providing care to a veteran with depression/anxiety, PTSD, and/or TBI is also particularly important since these caregivers tend to experience negative impacts at a disproportionately high rate.

- **Create condition-specific caregiver information packets and training.** These could be in the form of a series of online training videos and/or online training manuals. What caregivers would like to learn in this training is (a) what to expect with the illness/conditions, but also (b) what they can do to help the veteran, to make him/her comfortable, and to avoid problems/issues related to the condition. More than just listings of the services they should seek for themselves and the veteran, they need “how-to” instruction. For PTSD, there could be modules such as how to deal with conflict, what to do if the veteran is having a flashback, how to prepare for a visit to a public place, and how to help the veteran cope with a stressful situation. For diabetes, modules could include meal planning, how to monitor sugar levels, what to do if the veteran loses consciousness, and how to help with the veteran’s skin care. (These particular modules may already exist, in which case the focus should be on dissemination—see Recommendation 5.)

- **Offer a toll-free 24-hour phone line with support, information, and referral.** Caregivers would like a phone line that they could call with questions about what to expect with their veteran’s condition, how to handle an urgent situation as it is occurring, and to obtain referrals for local services including counseling, specialized medical care, home health support, respite, transportation, and meals. In addition, they would like the person on the phone to be a sympathetic ear, someone who can identify with caregivers of veterans.

2. Harness the Word of Mouth by Helping Caregivers Help One Another

Caregivers say they often learn about valuable resources and ways to help their veterans from other caregivers. If more caregiver-to-caregiver conversations were facilitated, caregivers could learn more from one another.

- **Develop a central website for caregiver support groups, forums, and blogs.** Create a website that would list both online and in-person caregiver support groups and forums, including basic information about each, such as the nature of the group in terms of the condition/illness that is the focal point, geographic area served, member composition, and meeting times or live chat times. Work with Web specialists to ensure that keyword searches on “caregiver” and the illness would allow caregivers to find these groups easily. If there are gaps between existing support groups, create online caregiver-of-veteran forums on PTSD, TBI, and other conditions, and/or perhaps organized by the period of time in which a veteran served.
- **Establish a caregiver peer mentoring program.** This could be facilitated by caregivers themselves if an online “matching” service were created for them. They could be matched on whatever characteristics were important to them—some may want a mentor in their geographic area or in their age group, and others may want a mentor whose veteran was in the same war or has the same condition.

3. Teach Caregivers About Resources That Are Available

- **Ensure that all caregivers receive a directory of both VA and other governmental and community programs and services.** Since the VA is such a critical resource for caregivers, they should be given a directory of all of the various departments, programs, services along with the phone numbers and/or e-mail addresses of key contact people. Caregivers also want lists of a wide range of other organizations that can help caregivers, organized by type of resource, along with contact information. A searchable online directory would also be helpful. To the degree that a local version could be created, that would be even more useful. Caregivers would like the list to be screened to ensure the resources are up to date. Some of the services they would like to see listed include:
 - VA benefits, including disability benefits and the claims process
 - Providers of respite, home health, hospice, assisted living, and special medical and rehabilitation therapies, including occupational therapy, physical therapy, speech therapy, and so on
 - Transportation services
 - Home modification services
 - Yard work, handyman, or cleaning services
 - Medical equipment suppliers
 - Sources of information about specific conditions or tips on how to care for certain conditions, including associations or foundations dealing with diabetes, paralyzed veterans, traumatic brain injury, etc.
 - Counseling providers, caregiver support groups, and peer mentoring programs
- **Teach caregivers about advocacy resources and methods.** Create an informational packet that informs caregivers what to do when they encounter resistance or “red tape” in obtaining services they need for the veteran or themselves. In addition to “how-to” information, the packets should include contact information for any ombudsmen offices within the VA and lists of veterans service organizations that provide advocacy services along with information about their specialty. Caregivers want advocacy services to help with paperwork, deal with bureaucratic “Catch-22s,” assist with appeals for benefits or services, and help make sure the needed medical care is delivered.
- **Create a list showing financial assistance available to veterans and their caregivers.** Prepare a detailed list of organizations that provide financial assistance for veterans or their caregivers, noting the criteria for who would qualify, and routinely provide it to caregivers of veterans. Examples of the types of financial assistance they would like included on the list are:
 - Medication and insurance co-pays
 - Home health aide services
 - Housing
 - Home modifications
 - Childcare services
 - Mental health services
 - Food programs
 - Social Security benefits
 - Incontinence supplies and other caregiving supplies
 - Travel and housing for recreational getaways that are offered to veterans and their families

- **Direct caregivers to legal assistance.** Caregivers need to know where to obtain reliable and inexpensive legal services related to caregiving. A list of places that would serve caregivers would be helpful. Ideally, a legal service would be able to explain what is needed and guide the caregiver through the creation of documents such as powers of attorney, advanced directives, or guardianships. A notary should be present in the office. The services should be available to the caregivers themselves, not just the veterans.
- **Facilitate caregiver searches for specialized care facilities.** When veterans need specialized care facilities, caregivers are often the ones to seek them out. It would help caregivers greatly if lists could be assembled for facilities offering specialized services that are commonly needed by veterans (e.g., speech specialists for veterans with TBI).

4. Help Caregivers Find Respite and Relief

- **Develop programs that connect caregivers of veterans with volunteers.** Many caregivers would greatly appreciate having access to a small group of local volunteers who could assist them with tasks such as yard work or house cleaning, prepare a meal, run an errand, or provide an occasional break from caregiving. While services that assist people to create a supportive community network already exist (e.g., “Lotsa Helping Hands”), caregivers who wish to receive help may not know of this or may feel uncomfortable recruiting volunteers for themselves. Support groups, religious organizations, and other community organizations could spearhead efforts to create these communities for caregivers in need.
- **Help caregivers find respite care.** Ensure that all caregivers who would benefit from respite care are aware of respite resources offered by the VA. In addition, compile lists of other organizations, including community volunteer networks, that may be willing to provide respite care.

- **Improve veteran transportation services.** Caregivers would be more likely to use transportation services for the veteran’s medical appointments if they were more dependable and if the pick-up was not so early and the return so late. A model transportation service would utilize staff who are sensitive to and able to handle special needs, such as dealing with PTSD behavioral/anxiety issues or a veteran’s need to stop and stretch periodically.

5. Improve Dissemination of Existing Resources

Some of the information or resources for which caregivers express a need may already exist. For example, some caregivers say they received a directory of where to turn within the VA for everything that they need. Or there may already be informational materials about what to expect with certain illnesses or how to provide care for them. If this is the case, then the challenge for organizations that provide support to caregivers is threefold:

- **Package existing information in a way clearly meant for family caregivers.** Caregivers need to understand that a resource is for them—rather than for veterans or patients, for example—before they will reach out to try it. Existing links to online information may need to be pre-tested to ensure that caregivers can find them and to ensure that caregivers recognize that the information may be valuable to them. Obtaining caregivers’ input would help ensure the usefulness of the information.
- **Evaluate existing materials to ensure they meet caregivers’ needs.** Some materials address the topics in which caregivers are interested, but do not go into enough depth or detail for them.

- **Improve methods for connecting caregivers to existing information.** The availability of materials and resources needs to be publicized using multiple different avenues if they are to reach the caregivers who need them. Besides the VA and non-VA health providers who have great potential to connect caregivers to helpful resources, the availability of resources could be publicized through brochures in pharmacies, radio public service announcements, community newsletters, association publications, and many other ways.

6. Sensitize Health Care Providers to Caregivers' Role

- **Periodically sensitize health providers about the important role that caregivers play in providing care to veterans.** Health care providers, both in the VA and in other organizations, are where caregivers first turn for information, and the more information and resources that these providers can give to caregivers, the better able caregivers will be to help the veteran. Further, it is important to include caregivers in care decisions—they can provide valuable input and they play an important role in ensuring that care plans are properly implemented.
- **Ensure that caregivers are shown how to properly administer medical treatments, care, or medications.** Half of caregivers of veterans have felt at some point that they did not know how to properly administer treatments or medicines to the veteran for whom they care (47%). Clearly, proper administration of treatments is critical to veterans' well-being, so it is critical to train caregivers.
- **Empower care managers to provide services for the caregivers themselves.** Care managers within the VA, non-VA health facilities, long-term care facilities, and veterans service organizations can be reminded of how helping the caregiver ultimately helps the veteran as well. It would be beneficial if care managers were encouraged and empowered to find services to help the caregiver as well as the veteran.

7. Provide Other Information and Tools to Support Caregivers

- **Help caregivers plan for veterans' transitions.** When a veteran is going to be transitioning home from a facility, entering a new facility, or moving for some other reason, caregivers need time to make preparations. They sometimes have to find an appropriate place for the veteran to live, make home modifications, purchase specialty equipment, or locate service providers. It would be helpful if health care providers and care managers were able to work with caregivers to plan for the transition well in advance.
- **Explain veterans' conditions to family members.** Having a health professional educate key family members about the veteran's condition and what they can do to help both the veteran and the caregiver would result in caregivers feeling more understood by family members and possibly more supported by them as well.

3. Are you a family caregiver of someone who served in the military? By this, we mean any unpaid relative or friend who helps care for the Veteran who needs assistance with everyday activities.

The unpaid care may include help with tasks such as personal care, bathing, dressing, feeding, giving medicines or treatments, help with memory tasks for someone with brain injury or Post Traumatic Stress Disorder (PTSD), transportation to doctors' appointments, or arranging for services, etc. You do not need to live with the Veteran.

Yes..... 1
No [TERMINATE] 2
Not sure [TERMINATE] 3

[TERMINATES: That concludes our questions. We are seeking family caregivers of Veterans. Thank you very much for your time.]

4. Please think about the condition for which the Veteran needs your assistance. Was the condition, or any aspect of it, caused by or related to military service?

Yes..... 1
No [TERMINATE] 2

MAKE "CONDITION" A HYPERLINK WITH THIS CLICK-IN DEFINITION: By "condition" we mean any illness (whether physical or mental), injury, disability, disorder, or any other physical/mental/behavioral problem for which the Veteran needs care.

[TERMINATES: That concludes our questions. We are seeking caregivers of Veterans whose conditions are related to military service. Thank you very much for your time.]

5. Is the Veteran...

Male 1
Female 2

PROGRAMMING NOTE: The Veteran's sex will be customized in the questions.
%his% indicates "his" or "her" should be used in the text.
%he% indicates "he" or "she" should be used.
%him% indicates "him" or "her".

6. How old is the Veteran you care for?

18 to 24 1
25 to 34 2
35 to 44 3
45 to 54 4
55 to 64 5
65 to 74 6
75 to 84 7
85 or older 8

7. In which of the following wars did the Veteran serve? *(Mark all that apply)*

- World War II 1
- Korean War 2
- Vietnam War 3
- Iraq – Desert Storm 4
- Iraq – Operation Iraqi Freedom 5
- Afghanistan – Operation Enduring Freedom 6
- Some other war or period of time (Please specify: _____) 7

8. Does the Veteran you care for have...? **[RANDOMIZE]**

(Please indicate a response of "yes" or "no" for each condition listed.)

		Yes	No
a.	A traumatic brain injury (TBI)	1	2
b.	Post traumatic stress disorder (PTSD)	1	2
c.	Any amputated hands, arms, feet, or legs	1	2
d.	Cancer (any form, including leukemia, melanoma, etc.)	1	2
e.	Diabetes	1	2
f.	Multiple Sclerosis (MS)	1	2
g.	Parkinson's disease	1	2
h.	Mental illness (e.g., depression, anxiety, etc.)	1	2
i.	Paralysis or spinal cord injury	1	2
j.	Blindness	1	2
k.	Other conditions: <i>(Please specify all injuries and illnesses resulting from military service: _____)</i>	1	2

9. a. Think about the various health professionals who initially dealt with the Veteran. Who were the FIRST to observe %his% service-related conditions once %he% was no longer in the military? **[ROTATE 1-2]**

[Even if you noticed the conditions first, please indicate what type of health professional saw them next.]

- All service-related conditions were first observed by VA health professionals 1
- All service-related conditions were first observed by non-VA health professionals 2
- Some of each 3
- Don't know 4

9. b. Within the past 12 months, through what provider(s) has the Veteran received health care?

- The VA 1
- A non-VA health provider 2
- Both 3
- Neither – The Veteran has not had health care in the past 12 months 4
- Don't know 5

10. What branch of service was the Veteran a part of?

U.S. Air Force	1
U.S. Army.....	2
U.S. Coast Guard.....	3
U.S. Marine Corps	4
U.S. Navy.....	5
Military Reserves	6
National Guard.....	7
Don't know	8

11. What is the Veteran's relationship to you? Is %he% your...

Friend/neighbor.....	1
Grandparent or great grandparent.....	2
Parent (father or mother)	3
Parent-in-law (father-in-law or mother-in-law)	4
Sibling (brother or sister).....	5
Sibling-in-law (brother-in-law or sister-in-law).....	6
Son or daughter	7
Son-in-law or daughter-in-law	8
Spouse	9
Partner or significant other.....	10
Uncle or Aunt, or great uncle/aunt	11
Other relative	12
Other non-relative	13

12. For how long have you been providing care for this Veteran? **[DROPDOWN]**

Less than 6 months	95
6 months to less than 1 year.....	96
1 year	1
2 years	2
3 years	3
4 years	4
5 years	5
6 years	6
7 years	6
8 years	8
9 years	9
10 years	10
etc. continue listing years thru 19	
20 to 29 years	25
30 to 39 years	35
40 to 49 years	45
50 to 59 years	55
60 years or more.....	65

13. When did you first take on a caregiving role?

- Within the first few months that the Veteran began needing care 1
- Some time later 2

14. Do you and the Veteran currently live in the same household?

- Yes 1
- No 2

15. **[IF PREVIOUS Q=NO]** Is the Veteran currently staying in a medical center, nursing home, or some other care facility?

- Yes 1
- No 2

16. With which of the following tasks do you help the Veteran? **[RANDOMIZE]**

	Help with this	Do not help with this
Getting in and out of beds and chairs	1	2
Getting dressed	1	2
Getting to and from the toilet	1	2
Bathing or showering	1	2
Dealing with incontinence or diapers	1	2
Feeding him or her	1	2
Giving medicines, pills or injections	1	2
Managing finances (such as bills or insurance paperwork)	1	2
Grocery shopping	1	2
Housework (such as dishes, laundry, or straightening up)	1	2
Preparing meals	1	2
Transportation (driving, helping arrange for transportation, or accompanying on public transit)	1	2
Arranging or supervising paid services (such as nurses, aides, Meals on Wheels, or other services)	1	2
Coordinating medical care and rehabilitative services	1	2
Advocating for %him% with care providers, government agencies, or schools	1	2
Administering physical or medical therapies or treatments	1	2
Reminding or giving cues about what %he% should be doing or helping with memory tasks	1	2
[IF TBI, PTSD OR MENTAL ILLNESS] Helping %him% cope with stressful situations or avoid "triggers" of anxiety or anti-social behavior	1	2

17. In a typical week, about how many hours in *total* do you spend helping the Veteran in *all* of the ways you just indicated? (*Your best estimate is fine.*) [NOTE: THE BREAK POINTS IN THE HOURS OF CARE CATEGORIES (8-9, 20-21, 40-41) ARE DEFINED TO BE COMPARABLE WITH NATIONAL CAREGIVING STUDIES, SO THE LEVEL OF CARE INDEX WILL ALSO BE COMPARABLE.]

- Less than one hour 1
- 1 to 4 hours 2
- 5 to 8 hours 3
- 9 to 20 hours 4
- 21 to 30 hours 5
- 31 to 40 hours 6
- 41 to 60 hours 7
- 61 to 80 hours 8
- More than 80 hours 9

IF NOT PRE-REGISTERED

At this point you are more than one-third of the way through the questionnaire.

If by chance your Internet survey session is interrupted, to avoid losing your responses, please provide your email address. We can then use it to send you a hyperlink to the survey that starts back in where you left off.

This is completely optional and your email address will not be shared.

Email address: _____

Prefer not to provide email address

 18. Who provides *most* of the unpaid care for the Veteran?

- You 1
- Someone else 2
- You and someone else about equally 3

19. How much caregiving has been provided to the Veteran during the past 12 months by...?

		None	A little	A moderate amount	A great deal	Don't know
a.	Other unpaid family members and friends	1	2	3	4	5
b.	Paid caregivers who help with daily activities (e.g., home health aide/nurse, personal assistant, adult day care)	1	2	3	4	5

19c. In the past 12 months, have you received any respite services from the VA or any other organization?

- Yes 1
- No 2
- Don't know 3

20. How many professional case/care managers or social workers does the Veteran have, if any, coordinating %his% care and assistance? (*Do not count yourself*)

- None [SKIP NEXT QUESTIONS] 0
- One 1
- Two 2
- Three or more 3
- Don't know [SKIP NEXT QUESTIONS] 4

21. **[IF THERE ARE 2+ CARE MANAGERS:** For the next two questions, please think of the one case worker or social worker who has spent the most time helping with the Veteran's case.]

Within what organization is the care/case manager or social worker employed?

[ROTATE 1-4]

- The VA 1
- One of the military branches 2
- A private insurance company 3
- A community agency..... 4
- A medical care or long term care facility 5
- Other (Please specify) 6
- Don't know 7

22. How helpful has the care/case manager or social worker been in locating, arranging, and coordinating suitable care and resources...

		Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Don't know
a.	For the Veteran	1	2	3	4	5
b.	For you, the caregiver	1	2	3	4	5

What to Expect

23. How confident in your caregiving skills did you feel at these points in time?

		Not at all confident	A little confident	Somewhat confident	Very confident
a.	During your first six months as a caregiver	1	2	3	4
b.	[SKIP IF Q12 <6 MONTHS] Nowadays	1	2	3	4

Caregiver Resource Needs

24. Have you looked for the following resources that may be available to you or the Veteran from any community or governmental organizations?

25. If yes, how easy or difficult were they to find...

		Have you looked?		How easy or difficult to find?			
		Yes	No	Very difficult	Some-what difficult	Some-what easy	Very easy
a.	Resources/services you need for the Veteran to coordinate %his% care	1	2	4	3	2	1
b.	Resources/services for your own health and well-being	1	2	4	3	2	1
c.	Resources/services to give you caregiver-related training or education	1	2	4	3	2	1

25d. Have you obtained any formal training about how to care for someone with your veteran's needs?

Yes 1
 No 2

26. Have you personally experienced the following challenges at any point since you became a caregiver? If yes, to what degree? **[RANDOMIZE]**

		Have you experienced this challenge?		
		No, not yet	Yes, to a minor degree	Yes, to a major degree
a.	Not knowing what to expect medically with the Veteran's illness or condition <small>Note: The word "medically" was added 7/30/10 6 pm after the first 223 completes.</small>	1	2	3
b.	Not knowing how to properly administer medical treatments, care, or medications	1	2	3
c.	[IF PTSD OR MENTAL ILLNESS] Not knowing how to address certain behaviors or problems related to %his% PTSD or mental illness	1	2	3
d.	Not being aware of services the VA has that can help you or your Veteran	1	2	3
e.	Not knowing where to obtain specialized care for Veterans such as rehabilitation, occupational therapy, speech therapy, etc.	1	2	3
f.	Not knowing how to arrange or pay for home modifications (e.g., ramps, grab bars, widened doors)	1	2	3
g.	Not knowing where to turn in order to arrange a break from caregiving from time to time	1	2	3
h.	Not knowing where to turn to obtain financial assistance	1	2	3

		Have you experienced this challenge?		
		No, not yet	Yes, to a minor degree	Yes, to a major degree
i.	Not knowing best how to plan the Veteran's transition into or out of different care facilities or locations	1	2	3
j.	Difficulty getting through bureaucracy in order to obtain services for the Veteran	1	2	3
k.	Being excluded from being a key player in decisions about the Veteran's care	1	2	3

27. Did anyone within the VA system or the D.O.D. military system proactively give you information (or links to information) to help you understand the Veteran's condition, treatment, or services?

Yes 1
 No 2

28. If you ever felt you needed to take a break from your caregiving, how easy or difficult would it be for you to get someone else to take on your caregiving responsibilities?
[ROTATE DIRECTION OF SCALE 4-1/1-4]

Very difficult 4
 Somewhat difficult 3
 Somewhat easy 2
 Very easy 1
 Not applicable, Veteran can be alone without a replacement 5

29. Did you turn to any of the following avenues to look for caregiver resources and information? **[RANDOMIZE]**

30. If yes, how helpful was this source?

		Did you turn to...?		How helpful was it?			
		Yes	No	Not at all helpful	Not too helpful	Somewhat helpful	Very helpful
a.	Word-of-mouth or asking around	1	2	1	2	3	4
b.	Support groups (in person)	1	2	1	2	3	4
c.	Blogs, online forums, or online groups	1	2	1	2	3	4
d.	The VA Benefits Administration	1	2	1	2	3	4
e.	The VA Health Administration	1	2	1	2	3	4
f.	Disease-specific organizations (e.g., M.S. Society, Brain Injury Foundation, American Diabetes Association, American Cancer Society, etc.)	1	2	1	2	3	4

		Did you turn to...?		How helpful was it?			
		Yes	No	Not at all helpful	Not too helpful	Somewhat helpful	Very helpful
g.	A non-VA health provider (e.g., a private doctor, clinic, hospital, or insurance company)	1	2	1	2	3	4
h.	Military OneSource	1	2	1	2	3	4
i.	Local government or community organizations (e.g., aging organizations, county programs, churches, Rotary Club, etc.)	1	2	1	2	3	4
j.	National Resource Directory website	1	2	1	2	3	4
k.	The D.O.D. military system	1	2	1	2	3	4

Caregiver Personal Health and Well-Being

31. How emotionally stressful would you say that caring for the Veteran is for you?

Not at all stressful					Extremely stressful	
1	2	3	4	5		

32. How much of a physical strain would you say that caring for the Veteran is for you?

Not a strain at all					Very much of a strain	
1	2	3	4	5		

33. How much of a financial hardship would you say that caring for the Veteran is for you?

No hardship at all					Great deal of hardship	
1	2	3	4	5		

34. As a result of becoming a caregiver, which of the following health problems, if any, have you experienced? (Please select all that apply.) **[RANDOMIZE 1-11]**

- Increased blood pressure 1
- Weight gain or loss 2
- Increased stress or anxiety 3
- Sleep deprivation 4
- Misuse of alcohol or drugs 5
- Depression 6
- Generally getting sick more often 7
- Poor eating habits 8
- Delaying or skipping your own doctor/dentist appointments 9
- Less time exercising 10
- Strains, aches, pains 11
- Other health problems (Please specify: _____) 12
- None of the above 13

35. **[IF CARING FOR SPOUSE, CODE AS MARRIED AND SKIP THE QUESTION]**

What is your marital status?

- Married 1
- Not married, but living with a partner 2
- Divorced 3
- Separated 4
- Widowed 5
- Single, never married 6

36. Do you have any children under the age of 18 living in your home?

- Yes 1
- No 2

36a. Are you also an unpaid caregiver for anyone else with special health needs other than the Veteran?

- Yes 1
- No 2

37. As a result of the Veteran's condition or your caregiving, has the following occurred? **[RANDOMIZE]**

		Yes	No
a.	You had to move to a new city	1	2
b.	[IF CHILDREN < 18 IN HOME] You have spent less time with your [IF TAKING CARE OF OWN CHILD: other] children than you would like to	1	2
c.	[IF CHILDREN < 18 IN HOME] Your children or grandchildren experienced emotional problems or school problems	1	2
d.	You spent less time with friends and family	1	2
e.	[IF CG IS 40+] Your own retirement plans have been put into question	1	2
f.	[IF CG IS MARRIED, SEPARATED, DIVORCED] Strain was placed on your marriage	1	2
g.	You had to give up or postpone plans that you had to further your own education	1	2

38. Please indicate how much you agree or disagree with each statement.

[RANDOMIZE]

		Disagree Strongly	Disagree Somewhat	Agree Somewhat	Agree Strongly
a.	You feel isolated	1	2	3	4
b.	You do not have enough time for yourself	1	2	3	4
c.	You feel you don't have a life of your own anymore	1	2	3	4
d.	You hesitate to take your Veteran anywhere because you are afraid of what might happen	1	2	3	4
e.	You feel no one else really understands what you're going through	1	2	3	4
f.	You feel you are the only person who can provide adequate care to the Veteran	1	2	3	4
g.	You are proud of the support and assistance you provide	1	2	3	4
h.	Gaining new knowledge and skills from caregiving feels rewarding	1	2	3	4
i.	The experience of caregiving has been fulfilling for you	1	2	3	4

39. Do you feel you had a choice in taking on the responsibility of caring for the Veteran?

- Yes 1
- No 2
- Don't know 3

Employment

40. Have you been employed at any time since you began helping the Veteran you care for?

- Yes 1
- No 2

40a. **[IF YES]** What is your current employment status?

- Employed full time 1
- Employed part time 2
- Not currently employed 3

41. **[IF EVER EMPLOYED]** As a result of caregiving for the Veteran, did you ever...
[RANDOMIZE]

		Yes	No
a.	Take unpaid time off from work or stop working temporarily	1	2
b.	Cut back the number of hours in your regular weekly job schedule	1	2
c.	Move to a job that pays less or provides fewer benefits, but that fits better with your caregiving schedule or responsibilities	1	2
d.	Quit working entirely	1	2
e.	Take retirement earlier than you would have otherwise	1	2

Reactions to Caregiver Support Programs and Services

42. How helpful would the following services have been to you, if at all, in addressing the needs, challenges, and difficulties you have already faced as a caregiver? *Do not consider what might happen in the future. Assume these would be provided at no cost to you.* **[RANDOMIZE]**

Note: If you have used this type of service, indicate how helpful it actually was.

		Not helpful	Somewh at helpful	Very helpful	Do not need	Don't Know
a.	A transportation service for the Veteran's medical appointments	1	2	3	4	5
b.	A telephone help line for caregivers of Veterans	1	2	3	4	5
c.	Help for you and your family to plan transitions [e.g., out of a facility, from one city to another]	1	2	3	4	5
d.	Legal assistance to prepare a medical power of attorney or advanced directives	1	2	3	4	5
e.	A list of organizations that provide financial assistance for Veterans or their caregivers	1	2	3	4	5
f.	Periodically having someone qualified to come in and give you a break	1	2	3	4	5
g.	Counseling or therapy for you or your family	1	2	3	4	5
h.	A support group or online discussion group for caregivers of Veterans with conditions similar to the Veteran you care for	1	2	3	4	5
i.	Having a health professional explain the type of condition your Veteran has to other family members and friends, so they can understand the situation better	1	2	3	4	5
j.	[IF NO CASEWORKERS OR MORE THAN ONE] Having a single caseworker as a source of information for all of the Veteran's	1	2	3	4	5

	needs					
k.	Having access to a small group of local volunteers organized to assist you with tasks of your choosing	1	2	3	4	5
l.	Caregiver training on how to do caregiving tasks safely and effectively, and how to take care of yourself	1	2	3	4	5
m.	An advocacy service that helps you get what you need if you encounter resistance or "red tape"	1	2	3	4	5
n.	A mentor who has been a caregiver of a Veteran	1	2	3	4	5
o.	Assistance finding accessible housing	1	2	3	4	5
p.	A list of varied types of information or services you may need, along with phone numbers and web sites of the VA departments and community organizations that provide them	1	2	3	4	5

Demographics

The remaining questions are for statistical purposes only.

D1. What is your gender?

- Male 1
- Female 2

D2. In what state do you currently live? **[DROP-DOWN BOX, LEAVE OPTION FOR OUTSIDE OF THE U.S.]**

D3. Which of the following best describes the area where you live?

- Urban area 1
- Suburban area surrounding an urban area 2
- Small town 3
- Rural area 4
- Don't know 5

D4. What was the highest grade of school or level of college that you completed?

- Some high school or less 1
- High school graduate 2
- Some college/trade or business school 3
- Bachelors degree 4
- Post graduate work 5
- Graduate degree 6

D5. Are you... *(Check all that apply)*

- White 1
- African American 2
- Hispanic 3
- Asian 4
- Native American 5
- Other (Specify) 6

- D6 What was your total household income from all sources, before taxes, in the last 12 months? *(Please estimate)*
- No income 1
 - Less than \$15,000 2
 - \$15,000 to \$29,999 3
 - \$30,000 to \$49,999 4
 - \$50,000 to \$74,999 5
 - \$75,000 to \$99,999 6
 - \$100,000 or more 7
 - Decline to answer 8

Thank you so very much for the time and thought you put into this survey! The information will be used to help caregivers of Veterans.

KEEP ON THE SAME SCREEN, BUT SKIP THIS FOR PRE-REGISTERED INDIVIDUALS:
Before you go, we have one last opportunity to help further.

We will be conducting follow-up telephone interviews with some survey respondents. The interviews will last 45 to 60 minutes, and we will pay \$50 as a thank you for your time.

Are you willing to take part in such an interview? This is completely optional.

- Yes 1
- No 2

[IF YES] Please provide your name and the phone number where you would like us to call you. We will not share your phone number with anyone.

Name _____
Phone number (____) _____ - _____

Thanks again! We expect results of the research to be made available late in the year at www.caregiving.org.

If you wish to be entered into the drawing for prizes of \$100.00, please provide your name and mailing address.

Name Address City/State/Zip

Your information has been received and your survey is now complete.

Caregivers of Veterans – Serving on the Home Front

Report of Study Findings
November, 2010



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