

# Caregivers of Veterans – Serving on the Homefront

*Report of Study Findings  
November, 2010*



Conducted by



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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.

National Alliance for Caregiving  
4720 Montgomery Lane, Suite 205  
Bethesda, MD 20814

[www.caregiving.org](http://www.caregiving.org)

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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 Living<sup>1</sup> except for transportation.



<sup>1</sup> 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. Now 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

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.

### 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.

# Caregivers of Veterans – Serving on the Home Front

*Report of Study Findings*  
*November, 2010*

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