# Military Caregivers Program: Heart of Recovery Caregiver's Assessment of Responsibility Evaluation (CARE)

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## **Privacy Advisory**

**Authority:** Army Regulation 40-5 (25 May 2007) Preventive Medicine directs Army Public Health Center to conduct evaluations of regional and local programs in support of USAMEDCOM oversight responsibilities (at para 2-19.j. page 14).

**Purpose:** The Army Public Health Center (APHC) will collect information to provide feedback to the Office of The Surgeon General (OTSG) to help determine the best way to better serve those who provide caregiver support to military personnel in an effort to develop the Military Caregivers Heart of Recovery Program.

**Routine Uses:** The information will be used by and disclosed to APHC and OTSG personnel and contractors to coordinate development of the Military Caregivers Heart of Recovery Program.

**Disclosure:** Furnishing this information is voluntary.

### What is a Military Caregiver?

A Military Caregiver is someone who provides unpaid care and assistance or receives SCAADL for, or manage the care of, someone who is at least 18 years old and has an illness, injury or condition for which they require outside support. This 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, help coping with symptoms of Posttraumatic Stress Disorder (PTSD), transportation to doctors' appointments, or arranging for services, etc. You do not need to live with the person. Care and assistance are considered unpaid if you provide them without receiving financial compensation in exchange for doing so.

# What is the Military Caregivers Heart of Recovery program and why should I participate in this survey?

Military Caregivers enhance the quality of life for Service Members and play a vital role in facilitating and improving their recovery, rehabilitation, and reintegration. There are numerous military, veteran, corporate, agency, and nonprofit programs and services available to meet the needs of those who provide caregiver support. To streamline this information, the Care for Caregivers program is being developed by the Office of the Surgeon General (OTSG), in collaboration with numerous partners, to serve as a central location for services and resources that provide support to wounded warriors and their families. The Army Public Health Center (APHC) is responsible for evaluation of the Heart of Recovery program. We will be collecting information about your general health status, type(s) of caregiver support, needs, services and resources used or required to provide support. This information is being collected to provide feedback to OTSG to help determine the best way to better serve those who provide caregiver support to military personnel. If you provide care to more than one recipient, please refer to the person with whom you spend the most time when responding to this survey.

## Why is my participation in this evaluation important?

The Military Caregivers Heart of Recovery program is being designed to provide services, resources, and training opportunities to address the needs of persons who provide caregiver support to military personnel. As a caregiver, your participation in this survey is critical because this program will assist you, your family, your friends, and ultimately your care recipient. The information we learn from this evaluation will help us build a program designed specifically to meet your needs.

#### What information am I required to provide and what is voluntary?

Your participation in this survey is voluntary, and your information will be kept private to the extent permitted by law. You may complete some or all of the survey. If you are uncomfortable answering an item, you may skip that item and move on to the next item. You may discontinue participation in this survey at any time. Please do not take the survey more than once.

What are the potential risks associated with participation in this evaluation? The primary risk to you is emotional upset and discomfort as a result of completing the evaluation survey questions. Participation in this evaluation might also involve risks that are currently unknown or unforeseeable.

What are the potential benefits associated with participation in this evaluation? It is unknown whether you will get any benefits by taking part in this study. We do not know if the Military Caregivers Heart of Recovery program will be helpful to you. That is why this evaluation is being conducted. There may be no personal benefit from your participation, but the information gained by doing this evaluation may help others.

Who can I contact to ask questions about this public health evaluation? If you have any questions about this survey or evaluation, please contact the APHC Public Health Assessment Division at <a href="mailto:usarmy.apg.medcom-phc.mbx.hpwwebcontacts@mail.mil">usarmy.apg.medcom-phc.mbx.hpwwebcontacts@mail.mil</a>.

If you agree to participate in this survey, please press NEXT.

## **Section A. Introduction**

1. Are you over eighteen years of age? □ Yes □ No
2. Do you provide continuous supervision or assistance to a Service Member with any
of the tasks below, due to being wounded, ill, injured, or impaired (including menta
and physical conditions)? Please check all that apply.
☐ Cooking
□ Driving
☐ Using the telephone or computer
☐ Shopping
☐ Keeping track of finances
☐ Ensuring safety
<ul><li>□ Arranging paid services</li><li>□ Walking</li></ul>
☐ Standing
☐ Dressing
☐ Toileting
☐ Personal hygiene
☐ Eating
☐ Caring for wounds
□ Housework
☐ Recreational activities
☐ Scheduling and managing Military Command activities (e.g. mustering)
$\square$ Scheduling and managing medical services (e.g. scheduling appointments)
$\square$ Managing medications and/or medical equipment
$\square$ Assisting with physical therapy exercises
$\square$ Assisting with memory tasks
☐ Career planning
☐ Helping to cope with post-traumatic stress disorder (PTSD)
☐ Other. Please Specify:
☐ No, my Soldier does not require continuous assistance or supervision with
any tasks due to being wounded, ill, or injured.

3. What social, emotional, or spiritual support do you provide to your care recipient
Please select all that apply.
☐ Providing pet care
☐ Comforting my care recipient
☐ Discussing stressful topics with my care recipient
☐ Helping my care recipient relax
☐ Helping my care recipient with healthy living decisions
☐ Engaging in activities of faith (e.g. praying)
☐ Guiding my care recipient in meditation
☐ Providing inspirational/uplifting material
☐ Engaging in activities of faith with the care recipient
☐ Helping my care recipient deal with perceived disgrace or stigma
from others
☐ Other. Please Specify:
- Other. Fiedde Opeeny.
4. What best describes your care recipient?
☐ Army Active Duty
☐ Army Reserve
☐ Army National Guard
☐ Army Veteran (former Soldier separated from the Military)
☐ Army Other. Please Specify:
☐ Air Force Active Duty
☐ Air Force Reserve
☐ Air National Guard
☐ Air Force Veteran (former Airman separated from the Military)
☐ Air Force Other. Please Specify:
5. With what installation is your care recipient affiliated?
☐ Joint Base Lewis McChord (JBLM)
☐ Joint Base San Antonio (JBSA)
□ Fort Sill
$\square$ Fort Bragg
□ Other. Please Specify:

## **Section B. Caregiver Support**

This section will ask questions regarding your relationship to the Service Member to whom you provide care or assistance. If you provide care to more than one Service Member, please refer to the Service Member with whom you spend the most time (primary care recipient).

What is your relationship with your care recipient?
☐ Spouse ☐ Significant Other (Royfriand/Cirlfriand/Dortner)
<ul><li>☐ Significant Other (Boyfriend/Girlfriend/Partner)</li><li>☐ Parent</li></ul>
☐ Grandchild
□ Sibling
□ Aunt/Uncle
□ Niece/Nephew
□ Cousin ·
□ Friend
☐ Unit Member
□ Support Group Member
□ Other. Please Specify:
Approximately, how far away do you live from your care recipient?  ☐ I live with my care recipient  ☐ Less than 5 miles  ☐ 6-10 miles  ☐ 11-20 miles  ☐ 21-60 miles  ☐ 61-100 miles  ☐ More than 100 miles
Did you relocate to care for your care recipient? □ Yes □ No
Where is your care recipient currently residing?  ☐ At home ☐ In the hospital ☐ Extended-care facility ☐ Other:

10. Approximately, how many days <b>per week</b> do you provide support to your care recipient?    Less than one   One   Two   Three   Four   Five   Six   Seven
11. Approximately, how many hours <b>per day</b> do you provide support to your care recipient (on the days that you provide care)?  □ Less than 1 hour per day □ 1-4 hours □ 5-8 hours □ 9-12 hours □ 13-16 hours □ 17 or more hours
12. Please type the number of other people (besides you) who provide support to the care recipient from each category. SpouseSignificant other (e.g., girlfriend, boyfriend, partner)ChildrenExtended family (e.g., grandparent, grandchild, aunt, uncle, cousin)FriendsMilitary connectionsReligious organization membersHome health aide/nurse

## **Section C. Level of Caregiver Burden**

This section will ask questions regarding physical, emotional, and financial burden caused by providing caregiver support.

13. Approximately how much of your personal funds were used to provide caregiver support in the past 12 months?  □ I do not spend my own personal funds to provide caregiver support  □ Less than \$1,000  □ \$1,000-9,999  □ \$10,000-\$19,999  □ \$20,000-\$29,999  □ \$30,000-\$39,999  □ \$40,000-\$49,999  □ \$50,000 or more									
14. Please mark the appropriate re	esponse	for the o	questions bel	ow.					
	Neve r	Rarel y	Sometime s	Quite Frequently	Nearly Always				
Has providing caregiver support affected your ability to work?									
Do you feel that because of the time you spend with your care recipient you don't have enough time for yourself?									
Do you feel embarrassed over your care recipient's behavior?									
Do you feel angry when you are around your care recipient?									
Do you feel that your care recipient currently affects your relationships with other family members or friends in a negative way?									
Are you afraid of what the future holds for your care recipient?									
Do you feel your care recipient is dependent on you?									

	Neve r	Rarel y	Sometime s	Quite Frequently	Nearly Always
Do you feel strained when you are around your care recipient?					
Do you feel your health has suffered because of your involvement with your care recipient?					
Do you feel that you don't have as much privacy as you would like because of your care recipient?					
Do you feel that your social life has suffered because you are caring for your care recipient?					
Do you feel uncomfortable about having friends over because of your care recipient?					
Do you feel that your care recipient seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
Do you feel that you don't have enough money to take care of your care recipient in addition to the rest of your expenses?					
Do you feel that you will be unable to take care of your care recipient much longer?					
Do you feel you have lost control of your life since your care recipient's illness?					
Do you wish you could leave the care of your care recipient to					

	Neve r	Rarel y	Sometime s	Quite Frequently	Nearly Always
someone else?					
Do you feel you should be doing more for your care recipient?					
Do you feel you could do a better job in caring for your care recipient?					
Overall, how burdened do you feel in caring for your care recipient?					
Do you feel others scorn you because you care for your care recipient?					
15. How much has your caregiving	experie	ence help	oed you:		
	Not at all	Just a Little	Undecide d	Somewha t	Very Much
Grow as a person since caring for your care recipient?					
Learned to do things you didn't do before since caring for your care recipient?					

## Section D. Care Recipient

The next section will ask questions regarding the person to whom you provide caregiver support.

16. How old is your care recipient?  □ 18 to 30 years □ 31 to 55 years □ 56 to 65 years □ 66 to 80 years □ 81 years or older □ I don't know
17. How many times has your care recipient been injured on a named operational deployment (e.g., Operation Enduring Freedom)?  Unsure Never Once Twice Three times Four times Five times or more

18. Do	es y	our car	e recipi	ent have	any	of the	following	condition	ıs?	<u>Please</u>	select a	<u>all</u>
that ap	ply	and in	<u>dicate</u>	<u>whether</u>	they	were	service	<u>related o</u>	<u>r n</u>	ot:		

Amputation	Yes, Service Related □	Yes, not Service Related □	N o □					
Anger management issues								
Anxiety								
Burns								
Contusion								
Depression								
Dislocation								
Fracture								
Heart disease								
Internal injury								
Open wounds								
Post-traumatic stress disorder								
Sprains / strains								
Traumatic brain injury								
Sleep disorders								
Substance use or abuse								
Other health condition (including behavioral or mental health conditions).								
19. Please specify what other health conditions your care recipient has:								

## Section E. Health Status of the Caregiver

☐ Substance Use or Abuse

☐ Other. Please Specify:

This section will ask questions regarding your current health status. 20. In general, how would you describe your current health status? □ Excellent ☐ Very good ☐ Good □ Fair ☐ Poor 21. Do you have any of the following conditions? Please select all that apply. ☐ Alzheimer's Disease □ Anxiety ☐ Arthritis ☐ Autoimmune Disease ☐ Asthma ☐ Bipolar Disorder ☐ Cancer ☐ Chronic Kidney Disease ☐ Chronic Obstructive Pulmonary Disease (COPD) ☐ Cystic Fibrosis □ Depression  $\square$  Diabetes ☐ Glaucoma ☐ Heart disease □ Injuries ☐ Muscular Dystrophy ☐ Obesity ☐ Osteoporosis ☐ Parkinson's Disease ☐ Physical Impairments ☐ Post-traumatic Stress Disorder (PTSD) ☐ Schizophrenia ☐ Sleep Disorders

# 22. Please mark the appropriate response for the questions below.

	any	hout , culty	li	Vith a ittle lifficulty	With some difficulty	With much difficulty	Unable to do
Are you able to do chores such as vacuuming or yard work?							
Are you able to go up and down stairs at a normal pace?				]			
Are you able to go for a walk for at least 15 minutes?				]			
Are you able to run errands and shop?							
23. During the past 7 da							
		Not at all		A Little Bit	Somewha t	Quite a Bit	Very Much
I feel fatigued							
I have trouble starting things because I am tired							
I feel run down							
My sleep is refreshing							
I have a problem with m sleep	у						
I have difficulty falling asleep							

24. During the past 7 days								
	Very Poor	Poor	Fair	Good	Very Good			
My sleep quality was								
25. Overall, how would you rate the current level of stress in your work life?    Much less than usual   Less than usual   About the same as usual   More than usual   Much more than usual								
26. Overall, how would you rate ☐ Much less than usual ☐ Less than usual ☐ About the same as usual ☐ More than usual ☐ Much more than usual	te the current le	evel of sti	ress in y	our perso	onal life?			

## **Section F. Services & Resources**

The next section will discuss the resources or services being used or needed to provide caregiver support.

27. What would help you become a more effective caregiver? Please select all that apply.
☐ Transportation
☐ Assistance accessing spiritual services
☐ Assistance navigating the military/VA health system/health insurance for my care recipient
☐ Access to short-term care for my care recipient
☐ Assistance with living arrangements
☐ Assistance acquiring life or disability insurance for my care recipient
$\square$ Assistance with creating a living will, advanced directive, or trust fund
$\square$ Assistance with assigning power of attorney, estate executor, or
custody/guardianship of your care recipient
☐ Assistance taking care of my personal responsibilities
$\square$ Assistance acquiring health insurance for myself
☐ Access to military healthcare resources for myself
☐ Access to healthcare resources for myself
☐ Flexibility with my job
$\square$ Assistance finding a job for myself
☐ Social support
☐ Child and family support
$\square$ Education or training to be a better caregiver
□ Other. Please Specify:

28. What resources or services have you used to provide caregiver support? Pleas	<u>e</u>
select all that apply.	
☐ Army Community Center	
☐ Army Family Team Building	
☐ Army Wellness Center	
☐ Army Wounded Warrior Program	
☐ Behavioral Health System of Care	
☐ Catholic Charities	
☐ Comprehensive Soldier and Family Fitness	
☐ Defense Center of Excellence	
☐ Defense Health Agency Clinical Support Division	
☐ Employment Readiness Program	
☐ Family Advocacy Program	
☐ Family Medical Leave Act	
☐ Family Overcoming Under Stress	
☐ Federal Recovery Coordination Program (FRCP)	
☐ G.I. Forum	
$\square$ inTransition	
☐ Military & Family Counseling Program	
☐ Military Warriors Support Foundation	
□ National Intrepid Center of Excellence	
□ Peer Support Coordinator	
□ Operation Comfort	
□ Operation Finally Home	
☐ Ready and Resilient Campaign	
☐ Recovery Care Coordination Program	
☐ Reintegrate, Educate, and Advocate Combatants in Health Care (REACH)	
☐ San Antonio Coalition for Veterans	
□ Soldier for Life	
☐ Soldier and Family Assistance Centers (SFAC)	
☐ Soldier for Life Transition Assistance Program	
☐ Strong Bonds	
☐ TRICARE	
☐ United States Army Reserve Care Coordination	
☐ United States Special Operations Command Care Coalition	
☐ United Way ☐ USO	
☐ Wounded Soldier & Family Hotline ☐ Wounded Warrior Project	
<ul><li>☐ Wounded Warrior Project</li><li>☐ Yellow Ribbon Reintegration Program</li></ul>	
☐ None of the Above	
☐ Other Please Specify:	

29. <b>Please select all</b> forms of assistance that were provided to you by the installation
once your care recipient entered the Military Treatment Facility:
□ Not applicable, my care recipient did not enter or visit a Military Treatment Facility
$\square$ Assistance traveling to visit your care recipient
$\square$ Assistance paying for food or gas
☐ Assistance acquiring local lodging
$\square$ Assistance getting acquainted with the installation
☐ Assistance completing Military Treatment Facility paperwork
□ Other. Please Specify:
$\square$ None of the above

# **Section G. Caregiver Support Training**

The next section will assess your desire for additional training	and education.
30. Would you be interested in participating in caregiver trainin ☐ Yes ☐ No	g?

## **Section G. Caregiver Support Training**

The next section will your specific training and education needs, if you indicated you desired additional training or education per the above question.

31. Which of the following topics would you be interested in learning more about?
Please select all that apply.
$\square$ My care recipient's condition
$\square$ Legal help for myself
$\square$ Career transition for myself
$\square$ Physical care skills (e.g. changing wound dressings, delivering medications,
assisting with activities of daily living, physical therapy exercises)
$\square$ Navigating visits to the doctor/hospital
$\square$ Navigating insurance companies
$\square$ Emotional support for myself (e.g. stress management, conflict resolution)
$\square$ Financial support for myself
☐ Caregiver support groups
□ Other. Please Specify:
32. How would you like to receive caregiver training? Please select all that apply.
$\square$ In person seminar training
$\square$ In person hands-on training
☐ Online webinar/tutorial
☐ Online discussion forum
$\square$ Smart phone application
$\square$ Other. Please Specify:
33. How much time would you be willing to spend in a training session?
☐ 15 minutes
□ 30 minutes
☐ 45 minutes
□ 1 hour
□ 2 hours
$\square$ More than 2 hours
24. How often would you like to receive correctiver training?
34. How often would you like to receive caregiver training?
☐ Once a week
☐ Once a month
☐ Once a quarter
☐ Twice a year
☐ Once a year
$\square$ Less than once a year

## **Section H. Caregiver Demographic Characteristics**

These few questions relate to **your** demographic characteristics. 35. What is your gender? ☐ Male ☐ Female 36. How old are you? ☐ 18 – 30 years  $\square$  31 to 55 years  $\square$  56 to 65 years  $\square$  66 to 80 years  $\square$  81 years or older 37. What is your marital status? ☐ Married □ Separated ☐ Divorced □ Widowed ☐ Never married 38. Are you Spanish/Hispanic/Latino? ☐ No, not Spanish/Hispanic/Latino ☐ Yes, Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or other Spanish/Hispanic/Latino 39. What is your race? Mark one or more races to indicate what you consider yourself to be. \_ ☐ American Indian or Alaskan Native ☐ Asian (e.g. Asian Indian, Chinese, Filipino, Japanese, Korean, or Vietnamese) ☐ Black or African American ☐ Native Hawaiian or Other Pacific Islander (e.g. Samoan, Guamanian, or Chamorro) ☐ White 40. What is the highest degree or level of education you have completed? ☐ Some high school, no diploma ☐ High school graduate, diploma equivalent ☐ Some college credit, no degree ☐ Associate's degree ☐ Bachelor's degree ☐ Master's degree ☐ PhD or Professional Degree

41. Which of the following best describes your current work status?  □ Full-time employee (for an external company or agency working 40 hours a week o
more)  Part-time employee (for an external company or agency working 1 or more hours per week)  Unemployed Self-employed Other. Please Specify:
42. What is your annual household income?  ☐ Less than \$25,000  ☐ \$25,000-\$49,999  ☐ \$50,000-\$99,999  ☐ \$100,000 or more
43. How did you hear about this survey? Please check all that apply.    Tip Card   Poster   Table tent   Facebook   Twitter   Mil website   Military Treatment Facility   Family Readiness Group   Other. Please Specify:
44. Is there anything else you would like to share about your experience being a caregiver? Please do not include any Personally Identifiable Information (PII) in your response.

The United States Army Public Health Center appreciates your participation in this survey. If you have any additional questions, please contact the Health Information Operations Program at <a href="mailto:usarmy.apg.medcom-phc.mbx.hio-program@mail.mil">usarmy.apg.medcom-phc.mbx.hio-program@mail.mil</a>.

The Wounded Soldier & Family Hotline at (800) 984-8523 (wsfsupport@conus.armymil) is available to help if needed. It operates 24/7 and offers wounded, injured, or ill Soldiers and their families a way to share concerns on the quality of patient care, provides senior Army leaders with visibility on medically-related issues, gathers information about medical care and suggests ways to improve medical

Please hit the submit button below to submit your survey.

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