

May 15, 2017

The Honorable David J. Shulkin  
U.S. Department of Veterans Affairs  
810 Vermont Ave. NW  
Washington, D.C. 20571

Dear Secretary Shulkin,

We applaud your recent decision to halt the revocation process and conduct an internal review of the Program of Comprehensive Assistance for Family Caregivers. Your decision is an acknowledgement that the VA cares about the success of this program and is committed to the difficult task of improvement. Now that you have the spotlight on this program, we urge you to capitalize on this momentum to implement changes that will improve its structure and support.

As you conduct the review, we, as organizations with a direct line to caregivers, would like to offer some perspective on the issues that have challenged this program since its inception. These thoughts are informed by the experiences and stories of caregivers themselves, and can be broken down into four main themes.

### ***Transparency***

Perhaps the greatest concern we hear is the lack of clarity and transparency in communicating aspects of the program to veterans, their caregivers, and outside partners. We encourage you to:

1. Mandate that upon revocation or tier lowering for failing to meet eligibility requirements, caregivers receive their veteran's eligibility assessment "scoresheet," within one week of the decision, so that they can prepare a proper appeal should they choose to do so.
2. Ensure that caregivers have a chance to provide feedback to medical care teams and Caregiver Support Coordinators (CSC) as they make eligibility and tier level determinations. Currently, many caregivers are not included in that process.
3. Establish an internal communications plan that originates in the VA Central Office and conveys clear and consistent policies across all Veteran Integrated Service Networks (VISNs).
4. Create a newsletter or listserv that disseminates up-to-date information about the program to military service organizations (MSOs), veteran service organizations (VSOs), and other not for profit organizations active in the caregiver space.

### ***Standardization***

Hand in hand with transparency comes standardization of Caregiver Program processes. Because each VA Medical Center operates as its own entity, the execution of the program can vary from VISN to VISN. While we respect each Center's ability to self-determine its own needs, when operational authority supersedes policy implementation, it creates an inconsistent, and at times unfair, program environment for caregivers. To remedy this, we recommend the following:

1. Grant the National Director (Meg Kabat) more operational authority to ensure that national policy is executed properly on a regional level. Limit the VISN's authority to change or adapt Caregiver Program policy in the course of their day-to-day operations.
2. Finalize and disseminate a policy directive that establishes a standard appeals process and clarifies eligibility requirements.

3. Update and improve the notices that caregivers receive upon being removed or lowered a tier within the program. Ensure that caregivers who are not removed for cause continue to receive their stipend for 90 days after removal to allow for adjustment and minimize financial burden.
4. Create an organizational document or flow chart (similar to the Integrated Disability Evaluation System (IDES) timeline) detailing the structure of the VA Caregiver Program, the appeals process, and points where the veteran and caregiver must make decisions.
5. Update the VA Caregiver Program website regularly to reflect the most accurate information, including the final “Roles and Responsibilities” document.
6. Keep the moratorium on program removal in place until the identified issues have been addressed.

### ***Education***

Many of the obstacles to the success of the VA Caregiver Program can be overcome through education of caregivers, service providers, and the public. Right now, many caregivers do not understand the scope and nature of the program, and we, as organizations, do not always feel empowered to give them accurate information. There are several ways to address this:

1. Begin communicating with caregivers and veterans before they enter the VA system (i.e. through TAP, the IDES process, within Warrior Transition Units, etc.).
2. Create a guide for caregivers and family members that communicates all of their options for support within the VA system (not just the Caregiver Program).
3. Implement grand rounds training with key service providers and medical facility staff to educate them on the importance of the caregiver in the recovery of the veteran.
4. Communicate updates and changes within the Caregiver Program to caregivers, not for profit organizations, and other partners to ensure that we are communicating the most accurate information to our constituents.

### ***Validation***

Caregivers are invaluable in the recovery and support of our nation’s veterans. And yet many times they are still not regarded as integral members of the veterans’ care team. As part of its commitment to becoming the best customer service organization in government, the VA must fully embrace the caregiver and family members as partners in the path towards rehabilitation and recovery.

1. Currently, the revocation and tier lowering processes feel like a penalty for the caregiver, who may not be financially or emotionally prepared to leave the program. Upon improvement of the veteran, the VA should begin to regularly check in with the caregiver to prepare him or her for the possibility of revocation or tier lowering. Such an initiative could include referrals to employment programs, messages of encouragement, and information regarding other programs offered by the VA.
2. Caregivers largely neglect self-care in favor of their caregiving responsibilities. Instituting “wellness checks” for caregivers in tandem with their veteran’s medical appointments would ensure that the caregiver is taking proper care of his/her mental and physical health, thus preventing caregiver burnout and illness.

We hope these recommendations will be useful to you as you conduct your review in the weeks and months ahead. Please call upon us to assist you as you undertake this tremendous task; the burden of ensuring support for these caregivers does not – and should not – fall to the VA alone. As military community organizations dedicated to championing caregivers, we are committed to working with you to support, educate, and inform caregivers nationwide.

Sincerely,

The Elizabeth Dole Foundation

AARP

America's Warrior Partnership

American Legion

American Legion Auxiliary

ARCH National Respite Network and Resource Center

Blue Star Families

Caregiver Action Network

Code of Support Foundation

Dog Tag Inc.

Easterseals

Give an Hour

Hope For The Warriors

Iraq and Afghanistan Veterans of America (IAVA)

Military Child Education Coalition

Military Officers Association Of America (MOAA)

National Military Family Association

Paralyzed Veterans of America

PsychArmor Institute

Quality of Life Foundation

Rosalynn Carter Institute for Caregiving

Square Deal for Vets

Wounded Warrior Project

Yellow Ribbon Fund