

Veterans' Family, Caregiver and Survivor Federal Advisory Committee September 2021 Recommendations

Recommendation 1: *Increase collaboration to offer evidence-based, caregiver survivor peer support for grief and bereavement.*

Rationale: Given the increase in Veteran deaths from COVID-19, chronic illness from toxic exposure, and sudden loss from suicide, families and caregivers are increasingly struggling with the experience of grief and bereavement. Research and focus groups have shown that they need—and benefit from—the trusted, culturally sensitive, and skilled grief and bereavement support not only from trained clinicians but also from trusted peers.

The VA and its relevant programs can best help meet this increased need for caregiver survivor peer support in the near term by increasing its collaboration with, and referral to, established, evidence-based programs offering: grief and bereavement support; peer support training, matching and supervision; care and benefits assistance navigation services; and/or 24/7 grief and bereavement helplines.

Verified programs offering these services, especially from military, veteran, non-profit and faith-based organizations with existing relations with the Department and its relevant programs in the VA Office of Survivor Assistance, the VHA Office of Hospice Care Service and the Center for Development and Civic Engagement, and the Veterans Experience Office (MOAs) others, *should immediately* be engaged by the Department in an intentional coordinated effort to ensure that caregiver survivor family members— of all eras, all relations, all services, all causes of death— have access to these needed peer support services through the sharing of information, training and referrals to proven non-governmental programs, resources, and services.

The loss of a military or veteran loved one, whether expected or sudden, and the subsequent transition from caregiver to survivor can be an overwhelming time of mourning that can immobilize entire families and have lasting impact on their health and welfare.

Having a trusted source of compassionate caring from someone with similar lived experience to offer understanding, informed guidance and motivational hope is critical to the transition journey. This is especially important for those experiencing the loss of a veteran loved one from suicide given the frequent challenges to care and benefits access and the complexity of the suicide postvention grief journey.

Understanding how to assess the care, benefits and memorial services needed and available is daunting and overwhelming. It is critical that these individuals have access to information and assistance from both public private and non-profit sector professional providers to access the care and benefits and memorial assistance and as importantly from the essential understanding and mentoring of peer support in order to navigate the process.

Through the enhanced collaboration of existing VA and non-VA programs (especially those from Veteran, non-profit and faith-based organizations) the Department can: (1) keep the Secretary's commitment to the principles of service for Veterans families, caregivers and survivors published in the Code of Federal Regulations (38 CFR Part 0 Subpart A 0.603); (2) meet the goals of the Joining Forces initiative for collaboration between federal agencies and non-profit organizations to address the well-being of military and veteran families, caregivers and survivors; and (3) offer services without the unnecessary delay in the delivery of support, the diversion of dedicated personnel or the additional and unnecessary expense of committed appropriations.

VA Response: Concur

VA supports this recommendation and agrees that caregivers and families are struggling with the experiences of grief and bereavement. The Department of Veterans Affairs (VA) will continue to work collaboratively with military, Veteran, non-profit and faith-based organizations, Veterans Health Administration (VHA) Office of Hospice Care Service, Center for Development and Civic Engagement, Veterans Experience Office, and others to help ensure that all caregiver survivor family members have access to needed peer support services. VA will continue to deliver resources through information sharing, training, and providing referrals to non-governmental programs, resources and services.

Recommendation 2: *Improve the engagement of, and outreach to, caregiver survivors of toxic exposure.*

Rationale: The increase in the number of caregiver survivors— who have experienced the loss of a Veteran due to chronic illness associated with their military service, especially from toxic exposure— has enhanced challenges in the military community. Sending increased requests to Congress, VSOs and non-profit organizations are trying to fill the needs of caregiver survivors. It is also renewing the Department's attention to the thousands of Veteran loved ones struggling to access and navigate the care, benefits, and memorial services they need and are entitled to both before, and after, their loved one's death.

The Department should present a plan for how they intend to strategically address the needs of these caregiver survivors by their intentional engagement in: (1) the consideration of policy; (2) the delivery of relevant services; and (3) the evaluation of policy and programs. This plan should facilitate improvements to the experience with benefits, care, and memorial services across the journeys of caregiver survivors. It should further be continuously updated, as this is an ever-evolving issue. This plan should be presented to the Federal Advisory Committee by March 2022.

Given the increased knowledge on the clinical impact of toxic exposure on Veterans health and welfare, the growing number of Veterans diagnosed with chronic conditions that are associated with their military service, the challenging experiences of caregiver

survivors – and their children and youth - who have cared for Veterans with toxic exposure, and increased Congressional attention to these Veterans and their families, it is critical for the Department to engage the caregiver survivor community in its development, execution and communication of a clear strategy that includes not only care and memorial services for the Veteran but care and benefits for their survivors. By involving caregiver survivors of toxic exposure in its efforts, the Department will help demonstrate its commitment to respect, understand and improve their experience.

VA Response: Concur

VA supports Recommendation 2 and will work collaboratively throughout the Department to produce materials and activities designed to improve engagement of, and outreach to, caregiver survivors of toxic exposure. This will include targeted outreach activities, digital communications, a public service announcement, and proactive media engagements to better disseminate information and reach a broader audience. VA will improve engagement and outreach to caregivers of survivors of toxic exposure through personal engagement, outreach symposiums and social media messaging. Additionally, VA will promote and share VA benefit resources with survivors.

VA will continue to educate and inform internal and external partners to improve the delivery of VA services and to engage our Nation's transitioning Service members and Veterans. VA is also educating providers on how to assess for environmental exposures, and then communicate risk to veterans and caregivers. VA clinicians are currently required to complete WRIISC Training Module 1: Assessing Deployment Related Environmental Exposures (TMS Course 33195) by December 31, 2022.

Recommendation 3: *Increase and share verified information on caregiver survivor resource and services.*

Rationale: Veteran caregiver survivors have expressed their critical need for assistance in accessing, understanding and successfully using the many sources of information on care, benefits and memorial services that they need and are eligible for and are entitled to. Navigating the tens of thousands of public-private and non-profit sector sites, finding verified resources and services and applying for their assistance is overwhelming—especially as they transition from their role as a caregiver to their role as a survivor.

The Department of Veterans Affairs— in collaboration with the Departments of Defense, Labor, Health and Human Service, other agencies and Military, Veteran, non-profit, and faith-based organizations— *should* enhance all its multichannel sources and content to ensure that the information it offers through public sources is consistent with its commitment to serve and support this important population.

These enhancements should utilize customer experience (CX) principles and practices consistent with the VA commitment to customer experience. They should specifically involve the voice of the Veteran caregiver and survivor community and the relevant external stakeholders that help serve them.

Products from this effort should include, but not be limited to:

1. The publication and multichannel presentation of a comprehensive, easy-to-use guide for survivors that outlines existing resources and services for Veteran families, caregivers and survivors. The existing [VA Survivors and Burial Benefits Kit](#) should be revised so that it is clearer, more understandable and easier to use (e.g. technical terms should all be defined and processes and programs explained).
2. The dissemination of information on, and access to this enhanced information should be done in a concerted effort to communicate most effectively with a wide range of stakeholders serving Veterans and their families, caregivers and survivors (e.g., educational institutions and employers, state and local agencies, funeral home directors, coroners' offices, military/veteran/non-profit and faith-based organizations, etc.) in order to enhance their understanding of the experience of Veteran survivors and the referral to VA's survivor care, benefits and memorial services.
3. The identification of existing verified resources and services that support military and veteran caregivers throughout their survivor journey should be undertaken starting with the examination of existing information sources such as the National Resource Directory (NRD), the Hero Care Resources (Aunt Bertha) and PatriotLINK and others. Gaps in resources and services should be identified and information collected and incorporated where available. When needed, new resources and service needs should be considered in collaboration with external stakeholders to increase responsiveness, expand reach and reduce redundancy.

VA should complete this recommendation by September 2022 and make these resources available to the public.

Grief is a long and complex journey. From prognosis to years after a loved one is gone, there are multiple opportunities to provide a bereaved, or soon-to-be bereaved, family and caregivers with helpful and preparatory resources. Many current VA resources are still difficult to access and understand and their use and benefit could be increased with user input. For example, attractive template of the [VA Survivor Quick Start Guide](#) means that a number of terms are left undefined and thus limit its utility.

All information, resources and guides should be reviewed, developed and published (hard copy and/or electronically) in ways that are demonstrated to help surviving family members navigate the myriad of care, benefits and memorial services available to them. By offering more clear, understandable and usable information to caregivers and survivors, and the providers and peers who assist them, across their journey they will be more able to anticipate and plan for the most likely moments that matter (e.g., legal and financial requirements) rather than to be introduced to the complex process of care, benefits and memorial services access during their time of grief.

VA Response: Concur

VA supports Recommendation 3 and agrees that navigating through the transitional role from caregiver to survivor poses a challenge during a difficult time in the survivor's life. VA will continue to educate and inform internal and external partners (to include state partnerships) to improve the delivery of VA benefit information and resources to survivors. VA will improve engagement of outreach to caregiver survivors through personal engagement, outreach symposiums, and social media messaging.

Additionally, VA will revisit its current outreach materials, communications plans and current resources to identify any potential gaps and to ensure these efforts remain in sync with VA's focus on customer experience. VA will partner with stakeholders and subject matter experts to update existing materials and identify any gaps in its current posture. VA will develop and deploy innovative responses to ensure an informative and supportive customer service experience.

VA will continue to work with the Acting Director, Post Separation Initiatives, Director of Survivor Assistance, Outreach, Transition and Economic Development Veterans Benefit Administration to ensure widest outreach for caregivers as they transition to survivors.

Recommendation 4: *The Department should conduct a formal, quantitative survey that analyzes the current veteran population in order to understand gaps and challenges that may exist for families with children. This survey should be completed by June 2022.*

Rationale: As we learn more about the caregiving community it has become abundantly clear that children have been left out of this demographic, despite the enormous impact that it has on their lives. Issuing a survey of this population will help the Department better understand their needs and create resources to assist them where necessary. Additionally, this is an investment in our country's readiness as 30% of military children end up enlisting in the military.

VA Response: Concur-in-principle.

VA has two projects that are relevant, both of which are being conducted under the umbrella of the Elizabeth Dole Center of Excellence for Veteran and Caregiver Research (SDR 18-313).

Title: Living in a Veteran Home (LIVE): assessing the lived experiences of youth in Veteran caregiving households

Objectives:

- Understand the lived experiences of youth in Veteran caregiving households and identify key "moments that matter" or domains that shape caregivers' lived experiences.
- Identify domains and metrics that matter that can inform an action plan for VA and other organizations and agencies to pursue to better support this caregiver group and assess its impact

- Identify informal and formal supports that can inform an action plan for VA and other organizations and agencies to pursue to better support this caregiver group

Time frame FY2023

Title: Elizabeth Dole Center of Excellence for Veteran and Caregiver Research:

Surveys of High Need-High Risk Veterans and their caregivers

As part of the work of the Center, we are surveying a national sample of Veterans identified using the high need, high risk list, and their caregivers. We are surveying them three times over a 12–18-month period to assess trajectories over time.

Objectives:

- To identify gaps in services experienced by high need - high risk Veterans and their Caregivers
- To assess the association between Veteran and caregiver trajectories and well-being over time

As part of this survey, we are asking about the presence of youth in these Veteran households. This will give us a sense of the presence of youth in these high-risk households. We have ~8000 responses to our first round of surveys.

Time frame FY22 Q2-Q3 (for first round survey results)

Recommendation 5: *The Department should present a plan for how it intends to regularly outreach and explain criteria to potential applicants to the Program of Comprehensive Assistance for Family Caregivers. The VA should develop material to send to those who have been denied from the program that includes information on the Program of General Caregiver Support Services (PGCSS), the Respite Relief Program, and any other resources that are available. Additionally, the application for PGCSS should be concurrent with the application for PCAFC and allow family members to apply for both programs simultaneously.*

Rationale: By overseeing the process to be admitted into PCAFC, the VA has access to a large group of caregiving families who are in need of assistance. When the VA issues a denial, they have an opportunity to cushion the decision and provide resources to these families. This would acknowledge that they are caregivers and have other options for assistance. By standardizing these materials, it would also aid external groups in their efforts to help families denied from the program.

VA Response: Concur.

VA concurs with Recommendation 5. VA via CSP is currently engaged in multiple efforts to enhance communication with Veterans and caregivers who are interested in participating in CSP's PCAFC and PGCSS programs. Efforts include more robust

communication letters which will integrate many of the topics listed above (i.e., information on PGCSS, available resources, etc.).

Recommendation 6: *The Department should establish a policy that clearly articulates that families enrolled in VA programs will not face retribution or lose their group status if they accept financial support from other government programs groups (e.g., SNAP benefits).*

Rationale: In anticipation of the return to a post-pandemic world, it is critical to address the financial impact that the pandemic had on military and veteran families. Even though it would help their family greatly, many are hesitant to utilize government aid in fear that it will impact their status in VA programs or cost them more in the end. With job loss and food insecurity impacting a significant portion of the military and veteran community, it is critical that the Department's policies are not adding unintended consequences to those seeking financial aid from other agencies.

VA Response: Concur-in-principle

VA cites concerns regarding statutory and regulatory requirements. VA must follow statutory and regulatory requirements when administering its benefits to Veterans, their families, and survivors. Therefore, with respect to VA Pension benefits, it must utilize 38 U.S.C. § 1503 and 38 CFR §§ 3.271 and 3.272 to determine which types of income are counted and excluded in determining income for VA purposes. It is important to note that the example of Supplemental Nutrition Assistance Program benefits, administered by the United States Department of Agriculture, would fall into excludable welfare income as described in 38 U.S.C. § 1503(a)(1) and 38 CFR § 3.272(a).

Recommendation 7: *Due to new thresholds set by [SAVE LIVES Act](#), the Department should establish a national registry for caregivers in order to track participants and their activity in PCAFC, PGCSS, and CHAMPVA in the next fiscal year.*

Rationale: The SAVE LIVES Act (P.L. 117-4) gave the Department of Veterans Affairs the authority to vaccinate caregivers in PCAFC, PGCSS, CHAMPVA beneficiaries, spouses, and veterans outside of the VA health system. This legislation offers the Department a unique opportunity to learn more about the caregiver population and contact them directly. Using this law as precedent, other benefits may be distributed to this group in a similar manner. By creating a national registry for caregivers, the Department and external stakeholders can disseminate important information more effectively, better understand their needs, and reduce the stigma associated with caregiving.

VA Response: Concur-in-principle

VA concurs in principle but does not support a separate national registry for caregivers. CSP utilizes the Caregiver Records Management Application (CARMA), which tracks caregiver and Veteran applications in PCAFC. CARMA is a new data system, and CSP has been focused on fine-tuning the system and PCAFC optimization. PGCSS is our

next area of focus in relation to CARMA integration. CARMA will eventually track all PCAFC and PGCSS participants. VA will collaborate with the CARMA contacts who are working with CHAMPVA.