

# THE JOURNEY OF LOVING, CARING, LOSING, GRIEVING, & **LIVING ON**

THE EXPERIENCES AND CHALLENGES OF AMERICA'S  
MILITARY AND VETERAN CAREGIVER SURVIVORS

**The Caregiver to Survivor (C2S) Partnership**  
Tragedy Assistance Program for Survivors (TAPS) | Elizabeth Dole Foundation (EDF)  
Red Cross Military and Veteran Caregiver Network (MVCN)

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# FOREWORD

***Far too many caring Americans—including the military and veteran caregivers of the nation’s one percent—have become bereaved caregiver survivors.***

In the past two years, 56.8 million U.S. adults, children, and youth caring for a loved one<sup>1</sup> have experienced loss. The pandemic contributed to these losses and added disproportionate harm to the economic, physical, and psychological well-being of caregivers.<sup>2</sup>

Military and veteran caregivers have not been immune. They have faced losses even before a loved one’s passing due to declines in health and ability, adjustments in roles and relationships, dashed hopes and delayed dreams. Caregivers often report living with a vague and prevailing sense of “ambiguous” or “anticipatory” grief well before a loved one dies.

Today far too many of them grieve the death of loved ones from COVID, exposure to toxins or burn pits during their service or from suicide. Too often they begin their bereavement journey as caregiver survivors ill-informed, ill-prepared, and insufficiently supported. These circumstances add unnecessary complexity to the most challenging experiences they may ever face—ones that will have a profound impact on all involved, including the children and youth who have been their hidden helpers—ones they should never have to face alone.

The Caregiver to Survivor (C2S) Project was designed to increase our collective understanding of the experience of military and veteran caregiver survivors along their journey of grief and bereavement. This report describes what we learned from them about what mattered most in the deepest moments of their grief, their struggles to navigate the complexity of care and benefits and the value of support from other survivors and resources during their bereavement. It also identifies recommendations and highlights actions underway by the C2S Partners.

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<sup>1</sup> International Alliance of Carer Organizations (IACO), Global State of Caring, March 2021, <https://internationalcarers.org/wp-content/uploads/2021/07/IACO-Global-State-of-Caring-July-13.pdf>.

<sup>2</sup> Ibid.

# MAJOR RECOMMENDATIONS

## **Recommendation 1**

- Increase resources and services for the entire caregiving survivor family before, during and after the death of a loved one

## **Recommendation 2**

- Expand the availability of grief and bereavement support to mitigate the profound, prolonged, and permanent impact of loss for the entire caregiving survivor family

## **Recommendation 3**

- Broaden research that can spur innovations in policy, programs, and practices to best serve all care receivers and caregiving survivors.

By continuing to listen closely, the C2S Partners pledge to collaborate with all who seek to understand the experience of military and veteran caregiver survivors and increase support along their journey of loving, caring, losing, grieving, and living on.

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*Koby Langley,*

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*On the Cover: Each June, a Michigan meadow becomes a sea of red Flanders poppies, white daisies, and blue bachelor buttons as a living tribute to SGT Mateo Donaldson, who died by suicide in 2015 after serving our country. Mateo's surviving parents planted the wildflowers to honor their son, never knowing the comfort it would bring to military survivors and to service members and veterans carrying invisible wounds.*

*Photo Courtesy Of: Angie Smith Photography + More*

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# INTRODUCTION

***Our nation’s military and veteran caregivers and caregiver survivors are the hands and hearts of a nation.***

The fortunate ones have been supported by family, friends, faith communities, and/or specialized organizations before and after their loved one’s death. Those in the military and veteran community, for example, may have already connected to specialized organizations like the Elizabeth Dole Foundation (EDF)<sup>1</sup> or the Red Cross Military and Veteran Caregiver Network (MVCN)<sup>2</sup>. Following their loved one’s death, they may have found comprehensive help as survivors from the Tragedy Assistance Program for Survivors (TAPS).<sup>3</sup>

Even those caregivers fortunate enough to start their journey with connections and support cannot escape the complex and compounding challenges awaiting them after the death of their military or veteran loved one. Those without sufficient support may find themselves alone with the overwhelming challenges of navigating benefits and accessing resources while mourning—often supporting grief-stricken children and youth. Without compassionate acknowledgement and appropriate and timely assistance, their bereavement can become prolonged traumatic suffering that cripples generations.

***Informed, we can better support their journey of loving, caring, losing, grieving, and living on. Together, we can reduce the potential for even greater and more prolonged suffering—especially for the youngest and most vulnerable of our military and veteran survivors.***

## THE CAREGIVER TO SURVIVOR (C2S) PARTNERSHIP

The Caregiver to Survivor (C2S) Partnership was formed by the three organizations in order to collect additional information on the experience of caregiver to survivor loss following a presentation to the Department of Veterans Affairs (VA) Veterans’ Family, Caregiver and Survivor Federal Advisory Committee (FAC). The FAC was struck by the increased number of military and veteran survivors and the lack of understanding of the full range of their experiences both before and after their loved one’s

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<sup>1</sup> Elizabeth Dole Foundation <https://www.elizabethdolefoundation.org/>.

<sup>2</sup> American Red Cross MVCN <https://www.redcross.org/get-help/military-families/services-for-veterans/military-veteran-caregiver-network.html>.

<sup>3</sup> TAPS <https://www.taps.org/>.

death. Members of the FAC were specifically interested in TAPS' presentation on its 2020 Illness Loss Survivor Survey in which 67% of all survivor respondents indicated that the service member or veteran they were grieving had required caregiving before they died.

The Elizabeth Dole Foundation (EDF) and the Red Cross Military and Veteran Caregiver Network (MVCN), both of which are known experts in supporting caregivers, and the Tragedy Assistance Program for Survivors (TAPS), the national non-profit organization providing professional peer-based emotional support to all those grieving the death of a military loved one, share the goal that all caregivers and caregiver survivors have access to the full range of beneficial support and services throughout their grief and bereavement journey.

The three C2S organizations identified the following objectives to better understand the experience of caregivers who become survivors and to identify needed and helpful resources, services, and support.

## OBJECTIVES

- **Identify research-informed bereavement interventions** to inform and improve the delivery of services and support to caregivers and caregiver survivors along their loss journey
- **Document the experience of caregiver survivors through surveys and feedback** to better understand their needs, challenges, and helpful resources, services, and support
- **Compile information on, and verify, helpful resources, services, and support** to expand access and identify and fill gaps
- **Share findings with stakeholders** to improve knowledge of resources and services and increase collaboration in the support of caregiver survivors
- **Recommend changes to policy, programs, and practices** to better support caregiver survivors

## APPROACH

- **Analyze key literature and research from studies on bereavement interventions** through the Elizabeth Dole Center of Excellence for Veteran and Caregiver Research (referred to as the Center)
- **Review relevant studies and surveys by stakeholder organizations and agencies** in consultation with experts in sudden loss, suicide, and grief and bereavement services
- **Capture the First-Person Experience of the Caregiver Survivor** using focus groups to capture qualitative data on the lived experiences of caregivers and caregiver survivors:
  - **Create focus group interview questions** based on information from the literature review, existing research, and reports on the caregiver and survivor experience
  - **Categorize feedback, comments, and recommendations** by key area including moments that matter, challenges, needed resources and services, and recommendations
  - **Identify opportunities for service recovery and recommend program improvements** including immediate actions for the C2S Partners and opportunities for stakeholders
- **Identify Needed and Available Resources and Services** and compile a list of helpful interventions, resources, and services identified by caregiver survivors and share it widely with stakeholders



## CHAPTER ONE

# THE EXPERIENCE OF LOSS AND DEATH IN THE MILITARY AND VETERAN CAREGIVER COMMUNITY

***The 5.5 million caregivers of wounded, ill, or injured service members or veterans have increasingly found themselves in transition from supporter to survivor, from giving care to needing caring, from managing to mourning following the death of their loved ones due to non-combat causes such as COVID, exposure to toxins or burn pits, and suicide.***

In FY 2020, 592,682 veterans died—many from chronic conditions, including toxic-exposure-related cancers associated with their military service.<sup>1</sup> VA estimates 3.5 million service members may have been exposed to toxins while serving after 9/11.<sup>2</sup> Veteran service-connected, illness-related deaths are expected to increase in the years ahead.

In addition to illness deaths, over 18,400 VA patients died from COVID since the pandemic began in March of 2020.<sup>3</sup> During this same period, 92 members of the Active, Reserve, and National Guard components died from COVID<sup>4</sup> while 77 service members died in conflict.<sup>5</sup>

The DOD *Calendar Year 2020 Annual Suicide Report*<sup>6</sup> indicated that 384 active-duty service members died by suicide, as well as 196 Reserve and National Guard members, bringing the total to 580. A Brown University report of June 2021<sup>7</sup> found that since 9/11, 30,177 active-duty personnel and veterans of the Iraq and Afghanistan Wars (post-9/11) had died by suicide—more than four times the number killed in the wars themselves.

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1 “Facts About the National Cemetery Administration; NCA Facts for Fiscal Year 2020,” Department of Veterans Affairs. Last modified August 13, 2021. [https://www.cem.va.gov/facts/Facts\\_About\\_NCA.asp](https://www.cem.va.gov/facts/Facts_About_NCA.asp).

2 Tom Porter, “Burn Pits and Toxic Exposures FAQs,” Iraq and Afghanistan Veterans of America (IAVA). May 7, 2020, <https://www.iava.org/blog/read-iava-burn-pits-and-toxic-exposures-faqs>.

3 Aaron Kassraie, “VA Daily Covid Admissions Reaches All Time High.” AARP. Last modified January 19, 2022. <https://www.aarp.org/home-family/voices/veterans/info-2020/coronavirus-visitor-restriction.html>.

4 “Spotlight Coronavirus: DOD Response,” Department of Defense. Last modified February 9, 2022. <https://www.defense.gov/Spotlights/Coronavirus-DOD-Response/>.

5 “Casualty Summary by Casualty Category.” Defense Casualty Analysis System. Last modified February 15, 2022. [https://dcas.dmdc.osd.mil/dcas/pages/report\\_ofs\\_type.xhtml](https://dcas.dmdc.osd.mil/dcas/pages/report_ofs_type.xhtml).

6 Department of Defense, *Annual Suicide Report Calendar Year 2020*, 15. September 3, 2021. <https://www.dspo.mil/Portals/113/Documents/CY2020Suicide%20Report/CY%202020%20Annual%20Suicide%20Report.pdf?ver=oOwlvDd-PJuA-igow5fBFA%3d%3d>.

7 Thomas Howard Suitt, III, *High Suicide Rates among United States Service Members and Veterans of the Post-9/11 Wars*, (Brown University, June 21, 2021), 27. [https://watson.brown.edu/costsofwar/files/cow/imce/papers/2021/Suitt\\_Suicides\\_Costs%20of%20War\\_June%2021%202021.pdf](https://watson.brown.edu/costsofwar/files/cow/imce/papers/2021/Suitt_Suicides_Costs%20of%20War_June%2021%202021.pdf).

The 2020 National Veteran Suicide Prevention Annual Report<sup>8</sup> includes lagging data from prior years and showed the rate of death by suicide for veterans for prior years did not increase significantly between 2017 and 2018. However, in 2020, reports showed the number of veteran suicide deaths had risen to 31.6 per 100,000 in 2019—far higher than for non-veteran adults and above the average of 17 reported in that year.<sup>9</sup>

Rising service-connected illnesses, COVID deaths, and suicide leave behind increasing numbers of new caregiver survivors some of whom are readily visible to the VA and the organizations dedicated to their support. For example, recent data from the VA’s Caregiver Support Program (CSP) indicates that approximately 8,500 caregivers withdrew from the Program of General Caregiver Support Services (PGCSS) between FY20 and FYTD22 (as of February 1, 2022) because the veteran died. Another 2,520 caregivers withdrew from the Program of Comprehensive Assistance for Family Caregivers (PCAFC) because the veteran died.<sup>10</sup> As of February 1, 2022, 11,020 new caregiver survivors were supported just from these two programs.

Data from the Tragedy Assistance Program for Survivors (TAPS),<sup>11</sup> has documented both the increase in the number of bereaved military and veteran survivors seeking its support and the difference in the cause of death of their loved one. In 2008, TAPS survivors reported hostile action as the leading cause of death (60%) and deaths by illness as the lowest cause. By 2021, more military survivors reported the death of a military loved one by illness (31%) or by suicide (27%) than by hostile action (4%). Of these, 64% were within one year of loss.<sup>12</sup> TAPS received the highest number of military and veteran survivors ever—9,246—or an average of 25 per day. This is largest number of new survivors since its founding in 1994.

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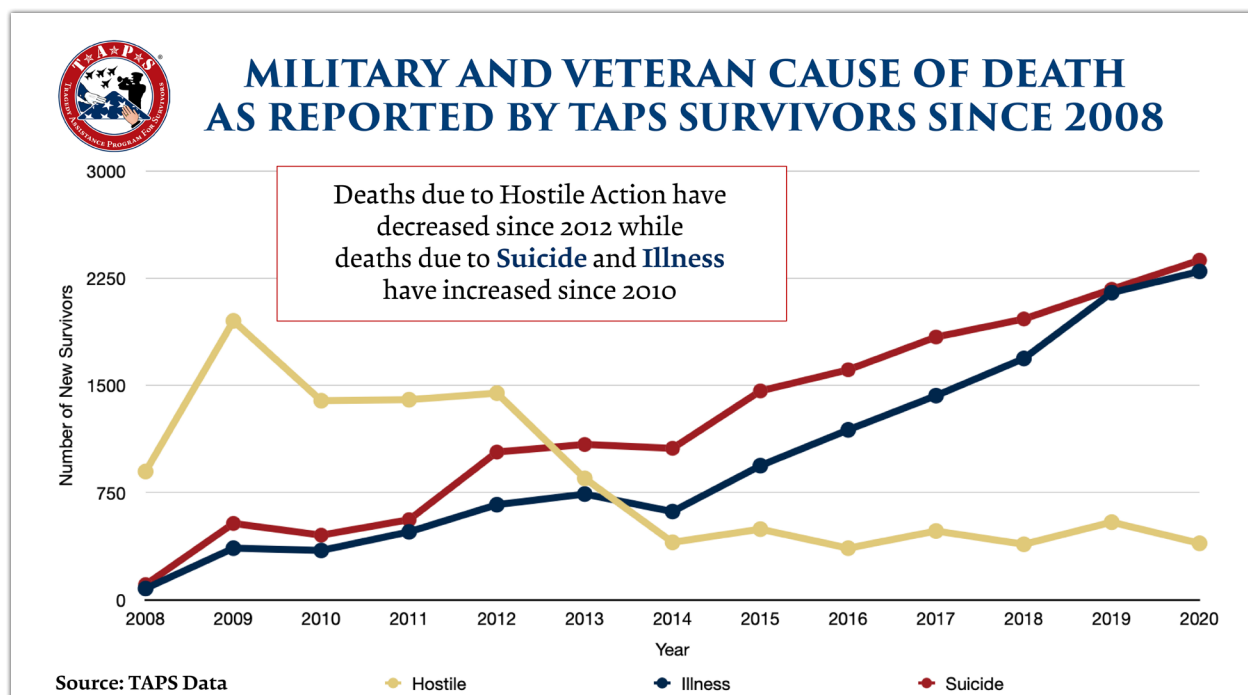
8 Department of Veterans Affairs, 2020 National Veteran Suicide Prevention Annual Report, 3, <https://www.mentalhealth.va.gov/docs/data-sheets/2020/2020-National-Veteran-Suicide-Prevention-Annual-Report-11-2020-508.pdf>.

9 “DOD and VA Health Care: Suicide Prevention Efforts and Recommendations for Improvement”, GAO-22-105522, Highlights, November 17, 2021. <https://www.gao.gov/products/gao-22-105522>.

10 VA Caregiver Support Program data provided to the Veteran Family, Caregiver and Survivor Federal Advisory Committee, February 16, 2022.

11 TAPS <https://www.taps.org/>.

12 Ibid.



**Deaths due to conflict or hostile action are no longer among the leading causes of death within the military community. Killed in action has been replaced by illness loss and sudden suicide loss as the primary reasons for loss of life.**

Deaths from all these causes added even more military and veteran survivors to the over 442,518 eligible spouses who were already receiving Dependency and Indemnity Compensation (DIC) following the death of their sponsoring service member.<sup>13</sup>

These caregiver survivors represent different generations and relationships (e.g., spouses, parents, siblings, and grandparents) and the cause of their loved one’s death varies (e.g., accident, illness, suicide). But they frequently report their caregiving had a substantial and lasting impact on their long-term well-being whether they were caring for someone with a chronic disease, an invisible injury, at risk of suicide, or aging.

**Survivors of all ages often find their care responsibilities have a negative impact on their health even before they experience the grief and bereavement that comes with their loved one’s death.**

<sup>13</sup> “VA Benefits & Health Care Utilization,” Department of Veterans Affairs, National Center for Veterans Analysis and Statistics. Last Modified October 26, 2021. <https://www.va.gov/vetdata/docs/pocketcards/fy2022q1.pdf>.

A study from the University of California's Department of Psychiatry reported that family caregiving can take as many as 10 years from a caregiver's life.<sup>14</sup>

Survivors must often mourn while they manage their own pains or diagnoses and continue to care for other family members. TAPS also shared that the number of adult survivors requesting professional mental health support for surviving children increased by 29% between 2019 and 2020. Among these requests, 29% of the children were grieving a loved one's death due to an illness and 38% were grieving a loved one who died by suicide.<sup>15</sup>

Finally, military and veteran caregivers who live with multiple challenges and chronic stress—sometimes for decades<sup>16</sup>—before they even begin their journey of loss may be at risk for experiencing prolonged grief or prolonged grief disorder (PGD). (PGD has been added to the upcoming revision of the Diagnostic and Statistical Manual of Mental Disorders, or DSM-5). Prolonged grief is a feeling of being stuck in an endless cycle of mourning that can last for years or even decades, severely impairing daily life, relationships, and job performance.<sup>17</sup>

The cumulative emotional, physical, and even financial losses caregiver survivors and their families sometimes face may contribute to the experience of prolonged grief, have a long-term impact on children and youth, increase the risk to those already marginalized, or complicate the response to trauma from multiple circumstances. Listening to the moments that matter to caregiver survivors along their bereavement and grief journey can provide valuable insights essential to understanding and the delivery of helpful support, resources, and services.

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<sup>14</sup> Derek Jones, WellSky®, "Are Family Caregivers at Risk of Premature Death from Stress?", October 10, 2011. <https://www.clearcareonline.com/blog/family-caregiving/the-deathly-dangers-of-family-caregiving/>.

<sup>15</sup> "2020 Impact Report, 19, TAPS, March 15, 2021, <https://www.taps.org/impact/2020>.

<sup>16</sup> Rajeev Ramchand, et al., *Hidden Heroes: America's Military Caregivers* (Santa Monica, CA: RAND Corporation, 2014). <https://www.rand.org/pubs/periodicals/health-quarterly/issues/v4/n2/14.html>.

<sup>17</sup> Dr. Kevin Fleming, Ph.D., Miles E. Drake, Jr., M.D., "Persistent Complex Bereavement Disorder DSM-5," Theravive®, 2011 <https://www.theravive.com/therapedia/persistent-complex-bereavement-disorder-dsm-5>.

## THE JOURNEY OF LOSS, BEREAVEMENT, AND GRIEF AMONG MILITARY AND VETERAN CAREGIVER SURVIVORS

***Caregiver survivors walk their journey of loss, bereavement, and grief while supporting others—including minor children and youth whose loss experience is developmentally complex—and trying to navigate the labyrinth of benefits, resources, and services.***

The death of a service member or veteran—whether anticipated or sudden—brings an end to the caregiving role and begins the role of survivor. This change in identity comes with new social, legal, and financial challenges and an unexpected emotional roller coaster.

While the specific experiences and expressions of grief and bereavement are unique to the individual, caregiver survivors often report a mix of feelings of denial, disbelief, disorganization, confusion, yearning, anxiety, fear, guilt, sadness, and depression<sup>1</sup>, as well as fatigue, disturbed dreams, distress, agitation, and even resentment. This is especially so if they have been living with multiple challenges and chronic stress sometimes for decades<sup>2</sup>—before they even begin their journey of loss.

Bereaved survivors—particularly those with sudden traumatic loss—are often at greater risk for living with depression and higher stress levels.<sup>3</sup> The bereavement experience of military and veteran caregiver survivors may also include the following:<sup>4</sup>

- **Isolation**—Restricted access to family, friends, and/or social groups limits opportunities to say goodbye, finish business, share memories, or exchange comfort and care

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1 Dr. Alan Wolfelt, “Grief Feelings,” Center for Loss & Life Transition®. <https://www.centerforloss.com/grief/im-seeking-help/> (accessed February 14, 2022).

2 Ramchand, Hidden Heroes.

3 Survivors of Suicide Loss Task Force, National Action Alliance for Suicide Prevention, Responding to Grief, Trauma, and Distress After a Suicide: U.S. National Guidelines, April 2015, <https://sprc.org/sites/default/files/migrate/library/RespondingAfterSuicideNationalGuidelines.pdf>.

Franklin James Cook, Linda Langford, Kim Ruocco, “Evidence- and practice-informed approach to implementing peer grief support after suicide systematically in the USA,” Taylor & Francis Online, July 13, 2017, <https://doi.org/10.1080/07481187.2017.1335552>.

Franklin James Cook, Linda Langford, Kim Ruocco, NIH, “Evidence- and practice-informed approach to implementing peer grief support after suicide systematically in the USA,” May 30, 2017. <https://pubmed.ncbi.nlm.nih.gov/28557695/>.

4 Paul T. Bartone et al. “Peer Support Services for Bereaved Survivors: A Systematic Review.” (Sage Journals, first published September 5, 2017, Issue published 2019, Volume: 80, Issue: 1, 137-166, <https://journals.sagepub.com/doi/10.1177/0030222817728204>).

- **Quarantines**—Impaired rituals related to dying and death, including holding funerals and memorial services, leave mourners unable to validate their loved one’s life
- **Traumatic loss**—Unexpected, sudden death and the inability to say final words which may have far reaching, unpredictable impacts on survivor’s health and functioning
- **Concurrent loss**—Required coping with the loss of a loved one and the loss of income and social support systems can overwhelm caregiver survivors

Caregiver survivors grieving suicide loss for example may be at even greater risk for post-loss bereavement experiences and their numbers may be far greater than previously recognized. According to the landmark report on the experience of sudden loss survivors, *Responding to Grief, Trauma, and Distress After a Suicide: U.S. National Guidelines*, the number of people affected by each suicide death was much higher than previously estimated. About 115 people are exposed to each suicide loss; approximately 21 of these feel a high degree of closeness to the deceased and 11 say the suicide had a devastating effect on their lives.<sup>5</sup> Other research has estimated 135 people are exposed to each suicide loss.<sup>6</sup>

TAPS’ experience supporting over 19,000 military-connected, suicide survivors—both those who were caregivers and those who were not—would substantiate the findings from the Guidelines report that ***“the severity and duration of suicide’s damage [for survivors] ... is far worse than is recognized, and that our society is not even close to responding adequately or effectively to lessen this damage or to help people recover from the tragedy that has befallen them.”***<sup>7</sup>

It is no surprise that caregiver survivors coping with these loss experiences in grief face challenges in identifying and accessing what resources and services they may need or are eligible for on their bereavement journey. The result can be a lack of access to relevant support—both before and after a military or veteran death. This can have a lasting, negative impact on the primary and secondary caregiver survivors (e.g., dependent children) if needs are not acknowledged and addressed in a timely, informed, and sensitive manner.

A respected reference for professionals supporting those in grief<sup>8</sup> identifies how reactions to death—especially for children and youth—are influenced by many factors such as age; ability; temperament; personality; relationships with caregivers, friends, and siblings; intelligence; home environment; community; and culture. Despite the

5 Survivors of Suicide Loss Task Force, *Responding to Grief, Trauma, and Distress*, 8.

6 Julie Cerel et al., “How Many People Are Exposed to Suicide? Not Six,” (*Suicide and Life-Threatening Behavior*, The Official Journal of the American Association of Suicidology, 2018), [https://losscs.org/wp-content/uploads/2018/05/Cerel\\_et\\_al-2018-Suicide\\_and\\_Life-Threatening\\_Behavior.pdf](https://losscs.org/wp-content/uploads/2018/05/Cerel_et_al-2018-Suicide_and_Life-Threatening_Behavior.pdf).

7 Survivors of Suicide Loss Task Force, *Responding to Grief, Trauma, and Distress*, iii.

8 Andy McNiel and Pamela Gabbay, *Understanding and Supporting Bereaved Children: A Practical Guide for Professionals*, (Springer Publishing Company, Inc., 2017).

multitude of factors influencing the survivor journey, we know the following about grief. It is:

- Personal and requires time and space
- Transitional and involves restructuring, regrouping, and adapting
- Seen and unseen, sometimes expressed and sometimes private
- Shared and happens in a context of relationships
- A process of integration or accommodating loss into the present

## A VETERAN SURVIVOR JOURNEY

The increasing number of veteran deaths from COVID, service-connected illnesses, and suicide has created more survivors and more caregiver survivors of all ages. It has also attracted additional attention from the public, state and federal agencies, and Congress. To better understand the experience of veteran survivors, and to help inform the delivery of care, benefits, and memorial services, the VA Office of Survivors Assistance (OSA)<sup>9</sup> interviewed survivors to create a Survivor Journey Map.

Recognizing that each grief journey is unique, and that loss may begin before and after death, survivors identified eight common “life stages.” The OSA Journey Map depicts these in sequence while acknowledging they may not occur in order, may never occur, or may even reoccur.

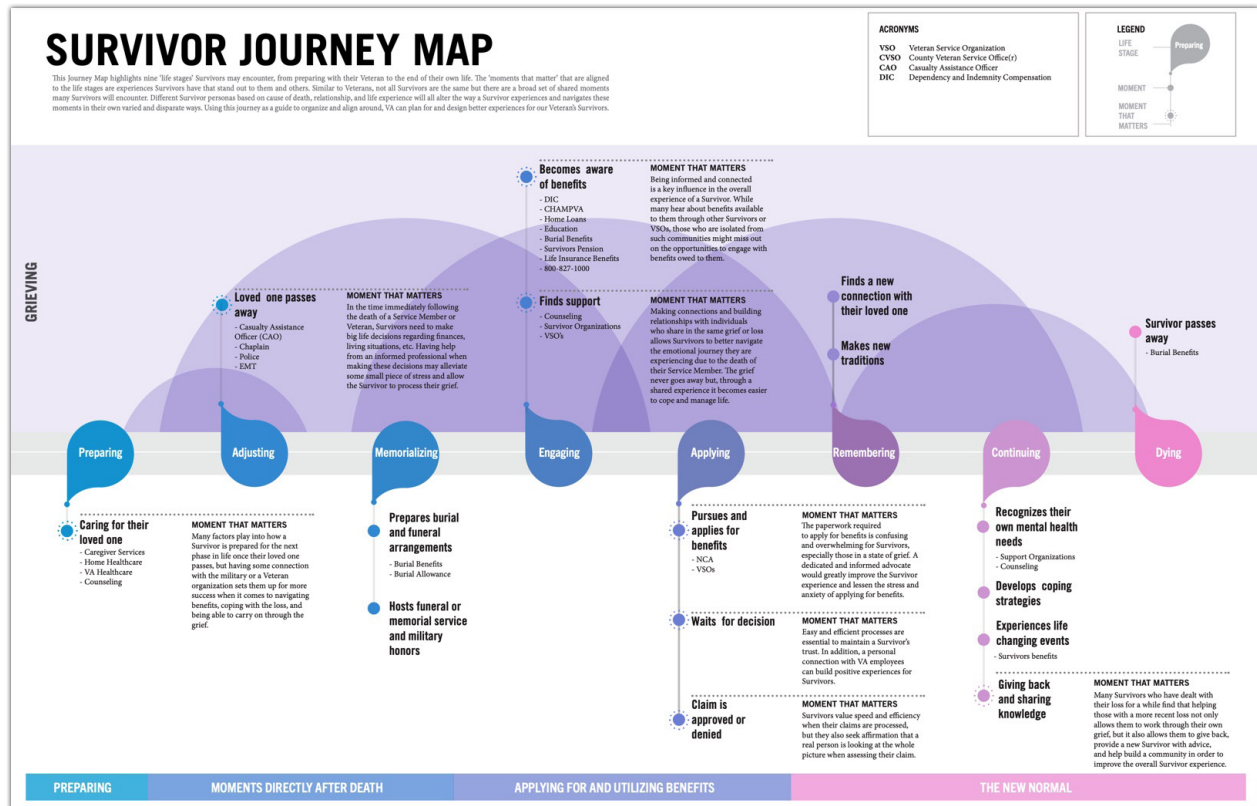
- **Preparing**
  - Caring for their loved one with the help of family, friends, and/or caregiver services
- **Adjusting**
  - Losing their loved one and engaging with new services and providers (e.g., chaplains)
- **Memorializing**
  - Preparing for burial and funeral home arrangements and accessing burial allowances
- **Engaging**
  - Finding benefits (e.g., pensions, life insurance, DIC, CHAMPVA, education assistance)
  - Seeking support with the socio-emotional response to grief (e.g., counseling/peer support)
- **Applying**
  - Applying for benefits and waiting for decisions while trying to manage life changes and grief
- **Remembering**
  - Developing new understandings of their departed loved one, making new traditions

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<sup>9</sup> Department of Veterans Affairs, <https://www.va.gov/survivors/>.

- **Continuing**
  - Recognizing their own mental health needs, developing coping strategies, engaging in giving back and sharing their knowledge and experience with others
- **Dying**
  - Coping with a caregiver passing away, family grief, and potential access to survivor burial benefits

Figure 2—Survivor Journey Map<sup>10</sup>



Even when survivors had different relationships to their veteran (e.g., spouse vs. parent) and the circumstances of death were different (e.g., cancer vs. suicide), survivors interviewed for the VA Journey Map said:

- **Professional or peer companionship, or connection to a military or a veteran service organization, led to a greater sense of “success”** in coping as survivors processed their grief, supported other family members, and made decisions on burial, finances, housing, work, or ongoing care for children and youth.

10 Department of Veterans Affairs, [https://www.va.gov/SURVIVORS/docs/survivor\\_jm\\_survivorfacing\\_v92.pdf](https://www.va.gov/SURVIVORS/docs/survivor_jm_survivorfacing_v92.pdf).



- **Agencies or organizations with dedicated advocates were seen as most helpful** as survivors dealt with the confusing and overwhelming benefits process.
- **Survivors with some time since their own loss who found a way to support those with a more recent loss found some meaning** in contributing to the healing of their peers in the military and veteran survivor community.

This feedback is consistent with that from caregiver survivors who participated in the C2S focus groups. Both sources help inform the VA and its administrations—including the Veteran Health Administration’s Geriatrics and Extended Care Programs like Palliative and Hospice Care—on how best to provide caregivers and caregiver survivors with more relevant, timely, and helpful resources, services, and support before, during, and after a veteran’s death.

The “life stages” reference used in the VA Survivor Journey Map is yet another way of trying to understand what Worden (2009)<sup>11</sup> referred to as the four tasks of mourning along the bereavement journey, namely to accept the reality of the loss, to process the pain of grief, to adjust to the world without the deceased loved one, and eventually to find an enduring connection with the deceased during their new life. These tasks may not be recognized or undertaken with intention but rather may be naturally evolving processes over months, years, or decades. Their navigation and resolution will impact the survivor for the rest of their life.

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<sup>11</sup> J. William Worden, *Grief Counseling and Grief Therapy*. New York, NY: (Springer Publishing Company, 2009).

## FINDINGS—FROM SURVEYS, FOCUS GROUPS, LITERATURE REVIEW, RESEARCH, AND STUDIES

### SURVEYS AND FOCUS GROUP FINDINGS—SUMMARY

- Lack of preparation for the ever-changing caring role(s) is a constant challenge.
- Having multiple, complex, changing role(s) is depleting—physically, emotionally, mentally, and financially.
- Managing the safety of self/family—before and after death—is a top priority.
- Stigmas create barriers to seeking help before and after death.
- Identifying and accessing resources and services is difficult.
- Accessing mental health services for all before and after death is hard.
- Planning and meeting legal and financial needs before and after death often requires assistance.
- Juggling ongoing caring roles—especially in grief—is almost impossible.
- Securing grief and bereavement support should not be left to chance.
- Securing peer support and a peer network in grief is lifesaving.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council report to Congress in the fall of 2021<sup>1</sup> included a comprehensive review of the current state of family caregiving from public comments and caregiver focus group participants. Like the respondents of the ***International Alliance of Carer Organizations (IACO) report, RAISE respondents identified social isolation and psychological burdens as challenges and recommended more social and emotional support***, suggesting shared elements across many survivors, despite the individual differences.

Although end-of-life issues were less frequently selected as most important by those actively involved in caregiving, more than one in five of the over 1,200 RAISE respondents indicated they were very important. The more challenging experiences reported by caregivers in the RAISE report included:

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<sup>1</sup> RAISE Family Caregiving Advisory Council, RAISE Family Caregivers Act Initial Report to Congress, September 22, 2021, <https://acl.gov/RAISE/report>.

- **Needing to fill multiple care, coordination, and administrative roles**

The navigation of the role of caregiver was found to be more complex and extend to more medical, administrative, and care coordination activities across public, private, and non-profit systems with separate, often conflicting case managers, records, and requirements. This was the reported caregiving experience of the C2S focus group participants of all eras, and it continued into their role as caregiver survivors trying to access care, benefits, and assistance.

- **Providing support without a formal assessment of the actual needs**

The civilian caregivers reported—as did the C2S focus group participants—that they often did things they did not know how to do, were never trained to do, did not have assistance to do, and/or did not feel comfortable doing.

- **Becoming financially, emotionally, and physically depleted**

The RAISE caregivers shared how their cumulative caring requirements and associated isolation often left them depleted. The C2S focus group participants acknowledged this and the vulnerability they felt when they became caregiver survivors and had to experience the new challenges of their bereavement journey.

These RAISE findings aligned with the survey feedback from TAPS survivors and with comments from caregiver survivors in the C2S focus groups as they reflected on the care they had provided before loss.

## TAPS ILLNESS LOSS SURVIVOR SURVEY FINDINGS<sup>2</sup>

For more than a decade, TAPS has seen a change in the type of loss that brings survivors to seek their services. Deaths due to hostile action have decreased since 2012 while deaths due to illness and suicide have increased since 2010.

In 2021, 9,246 newly bereaved military and veteran survivors came to TAPS for care; 31% were illness loss survivors, 27% were suicide survivors and 4% had a loved one die from hostile action. This is an average of 25 new adult survivors of all relations, all services, and all eras each day.

To understand changes in the cause of death and to better serve and advocate for the growing population of survivors, TAPS initiated an Illness Loss Survivor Survey in 2019 to collect data on the types of illnesses (e.g., toxic exposure) resulting in death. TAPS conducted a second Illness Loss Survivor Survey in July 2020 and a third in 2021.

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<sup>2</sup> TAPS, 2021 Impact Report, 2022, <https://www.taps.org/impact/2021>.

In 2021, the survey was sent to 7,090 adult military and veteran survivors grieving the death of their loved one who died by an illness and were six months or more post loss. The survey was accessed by 1,268 survivors. Of those, 984 respondents provided the following data about their loved one’s military branch of service, deployment assignments, and post-service health condition:

TABLE 1: TAPS 2021 ILLNESS LOSS SURVIVORS’ REPORT OF LOVED ONES’ MILITARY SERVICE

How They Served	Where They Served
64% served post-9/11	30% deployed to Iraq
43% served in the Army	24% deployed to Afghanistan
19% served in the Navy	15% deployed to Kuwait
15% served in the Marine Corps	31% deployed to other countries
14% served in the Air Force	

They also reported on their loved one’s age, health, and circumstances prior to death including their illness, diagnosis, treatment, and whether they required a caregiver prior to death:

TABLE 2: TAPS 2021 ILLNESS LOSS SURVIVORS’ REPORT OF LOVED ONES’ SYMPTOMS/CONDITIONS

Pre-9/11 Symptoms/Conditions	Post-9/11 Symptoms/Conditions
53%—cancer diagnosis	48%—cancer diagnosis
~ 38%—misdiagnosis	~ 40%—misdiagnosis*
42%—PTSD	37%—PTSD
39%—Depression	34%—Depression
32%—Anxiety	32%—Anxiety
~ 66%—required a caregiver	~ 55%—required a caregiver
* Reports of misdiagnosis of the illness/condition were more common for those who served in the Army and among post-9/11 service members between the ages of 31-40.	

Of those who died from illness, 36% were between the ages of 31–40 at the time of their passing, while 28% were between the ages of 41–50.

Of special note was the finding that 55% of post-9/11 illness loss survivors reported their loved one had

required a caregiver. Among this group, 84% had required a caregiver prior to their death before the age of 50. Another highlight was the report that 52% of all survivors had a loved one who had been diagnosed with cancer regardless of their era of service, their branch of service, or their location of deployment. Those illness loss survivors with a loved one who served post-9/11 felt their loved ones' condition had been misdiagnosed about 40% of the time with the highest rate among those with a loved one ages 31-40.

## C2S FOCUS GROUP FINDINGS

The C2S Partners recognized the critical importance of having first-hand feedback from caregivers and caregiver survivors. They used a narrative research approach to discover perceptions of caregivers and caregiver survivors before and after the loss of their loved one. The value of a qualitative, phenomenological study to discover perceptions is now routinely used by the Department of Veterans Affairs to capture the experience of those they serve. The C2S Partners applied this method with four focus groups to capture feedback about their journey directly from caregivers and caregiver survivors.

As shown in Table 3 below, the four focus groups were conducted across four population types—current caregivers of an ill service member or veteran from any era, caregiver survivors of an ill service member or veteran from pre-9/11, caregiver survivors of an ill service member or veteran from post-9/11, and caregiver survivors of suicide loss of a service member or veteran from any eras.

The focus group participants were recruited through their affiliation with three stakeholder organizations including the Elizabeth Dole Foundation (EDF), the Tragedy Assistance Program for Survivors (TAPS), and the Red Cross Military and Veteran Caregiver Network (MVCN). The C2S Partners note the need for additional studies to be initiated across a broader population of caregiver survivors including battle buddies, children, and youth.

Table 3 provides an overview of the era and status of participants in each of the four groups:

TABLE 3: C2S FOCUS GROUP PARTICIPANTS BY STATUS AND LOVED ONES' ERA

Status	Era	Number of Caregivers
Current Caregivers of Illness	All eras	6
Caregiver Survivors of Illness Loss	Pre-9/11	4
Caregiver Survivors of Illness Loss	Post-9/11	5
Caregiver Survivors of Suicide Loss	All eras	6

Table 4 shows a demographic breakdown of the participants' gender, race/ethnicity, age, and region within the U.S. This information was gathered through a pre-focus group demographic questionnaire asked of all participants. As described in the table below, most focus group participants were white women over the age of 45.

TABLE 4: C2S FOCUS GROUP PARTICIPANT CAREGIVER DEMOGRAPHICS

Demographic	Number
<b>Gender</b>	
Men	4
Women	17
<b>Race/Ethnicity</b>	
Black	2
Hispanic	1
White	18
<b>Age</b>	
25-44	3
45-54	7
55-64	7
65-75	4
<b>US Region</b>	
Midwest	0
Northeast	7
South	9
West	5

Participants were asked standardized questions about the moments that mattered most across their journey, their greatest challenges, and the resources needed—and available—to help. These questions were included in a moderator guide developed with subject matter experts and insights from caregivers, caregiver survivors, and caregiver survivors of suicide loss.

The focus group facilitated conversations were divided into nine topic areas:

1. Critical moments
2. Most significant resources and services
3. Informational resources and services
4. Medical and mental health resources and services
5. Grief resources and services
6. Financial resources and services
7. Legal resources and services
8. Home care, housing, and transportation resources and services
9. Education and employment resources and services

## KEY MOMENTS THAT MATTERED TO CAREGIVER SURVIVORS

Across the caregiver survivor journey—whether receiving a shattering diagnosis, stepping up to help provide hands-on care, juggling the management of home and work, struggling with end-of-life decisions and/or grieving the loss of a life cut short—focus group participants reported on what contributed to their experiences of anticipatory and ambiguous loss, bereavement, and grief before, during, and after their loved one’s death and the resources and services that were most helpful. Participants’ identification of the key moments that mattered are summarized in Appendix A.

All four of the C2S focus groups identified the following as challenges along their bereavement journey as caregivers and caregiver survivors:

**Lack of preparation for the ever-changing role(s) of caregiver and caregiver survivor is a constant challenge.**

Caregivers reported becoming not only direct providers, case managers, nurses, possibly wound care specialists, and pharmacists, they also had to fill the role of accountant, lawyer, benefits manager, information specialist, liaison and translator, and manager of all the services needed from others. They did this often without the benefit of firsthand experience with the military culture, and usually while lacking the knowledge and/or assistance needed to comfortably fill these roles.

Caregiver survivors reflected on the constant challenge they faced trying to fill ever-changing roles while caregiving. They felt especially unprepared to provide the complex care their veteran needed after outpatient procedures, discharge from the hospital, a change in diagnosis, or in response to an emergency. For example, some recalled having to call 911 in a panic to get answers to urgent questions. Most felt they lacked the information, understanding, skills, and assistance to fulfill the often-complex tasks and health care requirements needed to ensure the wellness of their loved one.

*“Nobody asks me the question: ‘Do you have funeral plans?’ I have to find all that out.”*  
—Pre-9/11 Caregiver

**Juggling multiple caregiving roles simultaneously is overwhelming.**

Many of these challenges continued for caregiver survivors as they tried to manage their grief while continuing to support other family members after their loved one’s death. This was both challenging and depleting, especially without the knowledge or assistance they needed. The physical, emotional, mental, and financial impact of caring for more than one person at a time adds up.

The need to manage the health, emotional well-being, and safety of oneself and other members of the family, before and after death, became daunting and things were left undone.

*“I was too overwhelmed to get care for myself while I was caring for three.”*  
—Pre-9/11 Caregiver Survivor

**Identifying and accessing needed information, resources, services, and support—before, during, and after their loved one’s death—is too complicated.**

Caregiver survivors rely on, and desperately reach out to, multiple resources and services. They use DOD, VA, and private and non-profit providers. Trying to find resources was difficult given their need to translate the acronyms and unclear eligibility requirements of agencies and organizations that seldom seemed designed with them in mind.



For example, confusion occurs because DOD Military Treatment Facilities (MTF) and VA Medical Centers (VAMC) do not have identical staffing and services to support medical specialties and non-medical needs (e.g., legal and financial). Nothing is easy or consistent. Complications increase when the veteran is simultaneously using the services of non-VA providers through the VA Community Care Network or private health insurance.

Survivors become frustrated trying to access information on resources and services, finding it unclear, not useful, or not available in a timely manner. They felt exhausted trying to identify help, arrange for care, coordinate services, manage records, and address mounting and confusing bills. This limited their ability to meet the care needs of their military member or veteran and address the safety, stability, health, and bereavement needs for themselves or their family.

**Planning for, and meeting, legal and financial requirements of caregiving and as a caregiver survivor is demanding.**

Caregiver survivors reported an almost universal lack of awareness of the extensive legal documents, such as a Power of Attorney (POA) and an Advanced Medical Directive (AMD), required to fully support their veteran's health care under all circumstances. Knowing about these and being able to complete them with assistance as caregivers allowed them to accompany their veteran during medical appointments and admissions. They felt better prepared to handle unexpected emergencies such as the decision to remove a ventilator and to prepare for future needs as a survivor.

After death, there were challenges understanding and executing wills, arranging for funerals, and accessing all relevant benefits (including for dependent youth). Without information or assistance, caregiver survivors failed to apply for, or receive, all the benefits they would be eligible for in a timely manner. Thus, they lost potential income or resources at a time when bills may have accumulated, expenses were increasing, and finding appropriately compensated employment was difficult.

*“Each VA Medical Center has different services and availability of personnel to support non-medical needs.”*  
—Post-9/11 Caregiver Survivor

**Coping with the mental health struggles, addressing resistance and stigmas, finding services and processing grief before, during, and after their loved one's death, was a constant challenge that has significant consequences.**

Finding support for the mental health challenges and bereavement of the entire family before and after loss was hard. Some families did not even recognize themselves as caregivers if they were supporting a loved one with an invisible wound (e.g., PTSD) or if their loved one died suddenly by suicide.

*“My kids were 14 and 18 when their father died by suicide—one sought help with difficulty, the other didn’t even try.”*  
—Post-9/11 Caregiver Survivor

It was a challenge to address the mental health needs (e.g., coping with isolation, trigger management, boundary issues) of the veteran, the caregiver, the family—including the needs of children and youth and/or parents or siblings—even before becoming a survivor.

*“I mean, I’ll be perfectly candid with you, I’ve had suicidal ideation. The grief is extreme, and it comes in waves and guilt. Did I do enough, the doubting . . . for me, now, feeling like I’m not a good enough parent and I didn’t sign up to do this alone.”*—Post-9/11 Caregiver Survivor

Caring for a loved one with an illness or injury—such as severe PTSD or undiagnosed traumatic brain injury—could be complex. If a veteran’s responses to circumstances might trigger anger or hostility, there could be a need to be vigilant to ensure everyone’s safety. Under certain circumstances, some found it necessary to request emergency assistance and/or leave the shared home.

*“. . . there was a point in the last year when I had to flee the house and call 911 just for a support system.”*  
—Pre-9/11 Caregiver Survivor

**Securing emotional support for anticipatory, complex, traumatic grief and bereavement—before during and after their loved one’s death—was often left to chance.**

It was often overwhelming to ensure everyone’s physical stability and safety while caregiving. Getting trustworthy guidance on how to manage the next tasks is also overwhelming, especially in the first months after a sudden loss when the experience of shock is so common. Despite the expansion of benefits to survivors under the PACT Act, caregiver survivors report that those benefits do not help them prepare for loss or adequately support their grief and bereavement following the death of their loved one.<sup>3</sup>

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<sup>3</sup> The PACT Act, <https://www.va.gov/pact/>

Finding immediate emotional support after loss, such as guidance on how to share with children and youth after a suicide loss, is important but hard to do. Caregiver survivors appreciated the non-intrusive companionship of a peer with lived experience to support them and other grieving family members (especially children and youth). Finding a peer support network in grief was seen as “lifesaving” and essential to begin to eventually find hope and healing for the future.

## ADDITIONAL MOMENTS THAT MATTERED TO CAREGIVER SURVIVORS

**Sacrificing careers and education to perform caregiving duties resulted in loss of income and future earning potential.** Caregiver survivors were often unable to work, or were limited in the jobs they could take, to meet their caregiving responsibilities. They were often conflicted if they were unable to work; they might regret the inability to pursue their professional goals and training but if needing to work they might resent being away from their loved one.

*“I mean, we had a home-based business. I had to sell it, because it was not feasible to run it and manage his care.”  
—Pre-9/11 Caregiver Survivor*

**Failure to see themselves as a caregiver, if their veteran had “invisible wounds” like PTSD, limited their understanding.** Caregiver survivors wished their role as a caregiver for their veteran had been recognized and explained to them early on. They felt this would have helped them better understand their situation and its responsibilities. One Vietnam era caregiver survivor acknowledged she might have also reached out earlier for help with her own emotional challenges had she been aware of the impact of this diagnosis on her.

*“That there was zero, nothing for us, when it came to caregiver health, caregiver support.”  
—Pre-9/11 Caregiver Survivor*

**Differences in services available to veterans, caregivers, and caregiver survivors by era of service can make it hard to find assistance.** The differences in the definition of survivor across organizations (illness vs. combat loss) can be confusing and frustrating and result in differences in eligibility for benefits, resources, and services. This can lead to the perception that some survivors deserve less concern or attention or have even earned less respect.

*“Most of the non-profits out there really only support the post-9/11 veterans and caregivers. There are a few that support both eras (TIF, EDF). Networking locally with the veterans’ organizations and the VA, I had very good responses.”—Pre-9/11 Caregiver Survivor*

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**Opportunity to guide other caregivers and caregiver survivors after time to process their own loss.** Along their bereavement journey, caregiver survivors often become interested in helping others avoid the difficulties and frustrations they experienced themselves (e.g., navigating bureaucratic systems to access care and benefits). They also find meaning in reassuring others that, despite their grief, they can go on.

*“Caregivers need help. They need the wisdom of the people who went ahead of them and who know about the things that we’re talking about here right now; we’re the veterans of this journey.” —Pre-9/11 Caregiver Survivor*

**Navigating and interacting with multiple systems of care was difficult.** Even with assigned case manager(s), they often felt lost and wanted just one person to provide them with overall direction.

*“And I was trying to figure out things and navigate pretty much on our own, because the hospital system was not, they didn’t believe us. We had to go to civilians.” —Post-9/11 Caregiver Survivor*

**Lack of support and resources for non-spouse caregivers (e.g., parents, siblings) made it challenging.** Non-dependent caregivers often had difficulties accessing information and applying for benefits and assistance both before and after the loved one’s death.

*“Everything needs to be clearer for those who are caregivers and in plain language, not riddled with military acronyms.” —Post-9/11 Caregiver Survivor*

**Struggles with the grieving process after death were compounded by being lost without the caregiving duties.** They felt their grief was unique with the end of caregiving and experienced the mixed feelings of loss, relief, and guilt.

*“It’s just this really complicated, messy sludge of every single emotion that you could possibly ever imagine happening in a three-year period. And then, oh, by the way, once you’re done with that, now you need to go grieve their death. It’s a completely different process.” —Post-9/11 Caregiver Survivor*

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**Frustrations filling out multiple forms and repeatedly needing to discuss their finances with different advisors to access services.** Some caregivers just stopped trying to get help because of the time and energy it required. They determined the effort was not worth the services being offered.

*“So just to get in the door with some of these organizations, you have to fill out this massive thing online and you have to give again, and again, and again.”—Post-9/11 Caregiver Survivor*

**Experiencing unexpected separations and isolation while caregiving and at death.**

Caregiver survivors reflected on heartbreaking circumstances that prevented them from being by their loved one’s side for medical care and/or during the dying process.

Caregiver survivors reflected they regretted the additional challenges their loved one faced when they could not accompany them to medical appointments or be present during home-based services like speech therapy because of conflicting responsibilities. They remembered how much their presence helped their loved one meet health regimens, accurately report challenges, request new services, and complete prescribed physical therapy exercises. Tragically, sometimes separations were unavoidable and even the caregiver’s full-time presence was not enough.

*“I did everything I could. I was taking care of us, but he wouldn’t do it unless I was home. If I wasn’t working, I could be home with him doing all that stuff and talking to him—he would have felt a lot better about stuff, but that’s not how it went down.”—Post 9/11 Caregiver and Suicide Loss Survivor*

Separation from a loved one during their last hours—whether due to the quarantine of the pandemic or the secrecy of a suicide—causes additional pain. COVID isolations were an indignity that separated loved ones during hospitalizations.

*“After years of marriage, I was unable to be by his side to help reduce his anxiety—it turned out to be his last night before taking his life.” —Pre 9/11 Caregiver and Suicide Loss Survivor*

*“I don’t think there is anything anybody can do about COVID restrictions, but I think they really need to consider a way for people who are mental health caregivers to be able to at least be on the phone with him and texting him... he was gone three hours after we got home from the ER that night.”—Post-9/11 Caregiver and Suicide Loss Caregiver Survivor*

**Appreciation for the value of peer grief support—especially for the sudden loss of suicide—was expressed by all caregiver survivors who had access to it.**

Caregiver survivors whose loved one died from suicide often feel a stigma and lack of understanding. Friends and family often have great difficulty trying to make sense of this loss and they may blame themselves, the veteran, or the system that let them down. Some organizations are less than prepared to help them in their grief and compound the feelings of isolation and the secrecy that surviving families may feel.

Having the understanding and lived experience of peers who have “walked the walk” of their specific grief can make a significant difference in the bereavement journey and long-term wellness of sudden loss survivors of all ages after their caregiving ends abruptly.

*“The VA referred me to TAPS and you guys have been nothing but a lifesaver for me. You paid for my therapy cause now I have a little bit of PTSD because of what I saw...”—Post-9/11 Sudden Loss Caregiver Survivor*

Recognizing that veterans and their caregiving families want more options and choice in their end-of-life care, the VA launched the Choose Home Initiative<sup>4</sup> in 2017. Its goal was to use VA Medical Centers’ personnel and their patients as co-collaborators in the creation of a comprehensive, integrated service delivery and support model to enable veterans who are aging and/or have complex care needs to choose to be supported at home instead of receiving institutional care.

The Initiative sought to improve the service navigation experience of veterans and caregivers in part by strengthening collaboration with services offered in the community. It also wanted to understand what beneficial home-based care services or interventions were, so it included the creation of the first VA Center of Excellence for Veteran and Caregiver Research.

The Center of Excellence for Veteran and Caregiver Research (referred to in this document as the Center) was established in October 2018 with funding from the VA Health Services Research and Development Service (HSR&D). It was named in honor of Senator Elizabeth Dole in recognition of her significant efforts to improve the nation’s understanding of, and support for, military and veteran caregivers. The Center has expanded the VA’s capacity to understand and deliver integrated veteran and caregiver-informed, data-driven approaches to care and it collaborated in the C2S project as noted below.

<sup>4</sup> Department of Veterans Affairs’ Choose Home Initiative report (available from the Department of Veterans Affairs Veterans Health Administration).

## LITERATURE REVIEW, RESEARCH, AND STUDIES FINDINGS—SUMMARY

- Research on bereavement experiences overall, and specific helpful interventions, is limited.
- There is a mismatch between survivors' reported needs and studied interventions:
  - Interventions tend to be narrow, but needs are multidimensional.
  - Interventions tend to target individuals not families.
  - Interventions' differential effects on types of survivors, needs, and circumstances are understudied.
- Outcome measures are limited and tend to rely on self-reporting.
- Evidence points to the effectiveness of:
  - Pre-bereavement interventions/intervening early are associated with better outcomes.
  - Peer support interventions help—even when remote—particularly for suicide survivors.

## THE ELIZABETH DOLE CENTER OF EXCELLENCE FOR VETERAN AND CAREGIVER RESEARCH FINDINGS

The Center identified 920 records of research, of which 85 met the criteria for a full-text review. Five studies stood out as relevant and were summarized in greater depth. The most common interventions noted in the relevant research were the peer support/TAPS model, group support, and interventions that include the Carer Support Needs Assessment Tool (CSNAT).<sup>5</sup> The most common outcomes assessed in relevant research were psychological distress (measured by general well-being, depression, and response to behaviors), symptom severity, and grief.

The Center's review of existing literature and research on the bereavement (Appendix B) and pre-bereavement (Appendix C) experiences revealed the following themes:

- **Research on bereavement experiences overall, and on helpful bereavement intervention specifically, is limited.** While many studies focus on caregivers/survivors of patients with cancer and dementia, few are high quality or report on interventions designed to improve survivor outcomes, and even fewer include military or veterans.
- **Research on bereavement shows the needs of survivors and the interventions provided**

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<sup>5</sup> Gunn Eli Grande et al., "Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial," 2015, <https://pubmed.ncbi.nlm.nih.gov/26719349/>.



**are often mismatched. Interventions tend to:**

- be narrowly defined even though survivors' needs are multidimensional. Interventions focus on specific aspects of the bereavement, i.e., depression, anxiety, and self-reported function. However, survivors have multiple needs, e.g., financial or legal readiness, and/or assistance understanding benefits and eligibility.
  - focus on individuals despite recognition that family system support is needed. Bereavement often occurs within a family system and though family-targeted interventions are needed, they are not well represented in the literature.
  - have differential effects depending on individuals' baseline needs and situations. These differences are underexplored in the design and execution of interventions. The baseline, context, functioning, and needs of caregivers and caregiver survivors should be assessed to provide the best individualized resources, services, and support.
  - rely on brief, self-reported outcome measures that may not reflect the totality and complexity of survivors' experiences, particularly daily life experiences.
- **Research on bereavement interventions indicates that those most effective tend to:**
    - occur early in the pre-bereavement period and lead to better outcomes. Interventions that engage the survivor early and even begin their support before the anticipated bereavement period, seem to be associated with better outcomes.
    - peer support interventions are effective across a broad range of delivery approaches, i.e., in-person vs. remote, particularly for those impacted by suicide.

The number of caregiver survivors experiencing sudden loss, including suicide loss, is increasing. Research shows that their experience can be complex and especially traumatic. A targeted search of studies on suicide loss was conducted to complement the Center's findings from its review of literature and research on bereavement interventions for caregiver survivors.

- **A systematic review<sup>6</sup> of the specific benefits of peer support services for bereaved adult survivors of sudden or unexpected death in 32 studies showed:**
  - peer support is helpful to bereaved, sudden loss survivors. It helps reduce grief symptoms and increases well-being, personal growth, and positive meaning in life.
  - peer support programs that are internet-based are also beneficial in part due to their easy accessibility.

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<sup>6</sup> Bartone, "Peer Support Services for Bereaved Survivors."

- peer support appears to be especially valuable for survivors of suicide loss perhaps because of its related stigma and the lack of support experienced by many suicide survivors.

The authors concluded the 32 reviewed studies related to bereavement, death, grief, peer support, recovery, and suicide provide consistent evidence that peer support is beneficial to bereaved survivors. Survey feedback from military and veteran caregiver survivors and survivors connected with TAPS and those participating in the C2S focus groups reinforced this finding of the value of peer support.

- **Another landmark report<sup>7</sup> on the experience of suicide loss survivors established that those exposed to a suicide loss may experience negative effects and that multiple levels of care and support are required to meet the full range of needs of those traumatized or affected by a suicide loss.** Research on the effectiveness of peer support practices and programs in mental illness and substance abuse recovery have informed the expansion of Peer Grief Support after Suicide (PGSS). Existing and emerging research found:

- the severity of suicide's impact on loss survivors is far worse than previously recognized.
- the suicide bereaved are an underserved population.
- peer support is generally helpful to the suicide bereaved as it is for mental illness and substance abuse recovery.
- the systematic development of peer grief support interventions is needed to help support survivors of suicide loss whose bereavement experience has qualities of its own, e.g., shock and confusion, persistent and painful uncertainty, deep feelings of shame, guilt, and fear, struggles with troubling moral and spiritual questions and being profoundly affected by trauma and stigma.<sup>8</sup>
- the existing Programs for Peer Grief Support After Suicide (PGSS) are decentralized and autonomous. There is no clear systematic understanding of the elements and principles that enable the delivery of effective peer support for programs and organizations.
- the Tragedy Assistance Program for Survivors (TAPS) offers comprehensive services to the military and veteran suicide survivor population and is a national model for such PGSS systems development.

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<sup>7</sup> Survivors of Suicide Loss Task Force, Responding to Grief, Trauma, and Distress.

<sup>8</sup> Ibid.

## RECOMMENDATIONS—FROM SURVEYS, FOCUS GROUPS, LITERATURE REVIEW, RESEARCH, AND STUDIES

### SURVEYS AND FOCUS GROUP RECOMMENDATIONS—SUMMARY

- Provide potential caregiver survivors with timely and clear information, explanations, and training to help them plan for their role and responsibilities before and after loss to prepare them for changes in prognosis and treatment regimens including referrals to palliative and hospice care and transfers to assisted living facilities (ALF) and community living centers (CLC)
- Assess all care receiver and caregiver needs to address the full range of their current and future care and support requirements (e.g., legal, financial, health, mental health, information, training, care support and assistance, housing, and employment) before, during, and after loss
- Create a customized, comprehensive, evolving support plan to address all the needs (e.g., legal, financial, health, mental health, information, training, care support and assistance, housing, employment) of the care receiver and caregiver before, during, and after loss
- Increase the sharing of information on the full range of relevant, verified grief and bereavement resources, services, and support (e.g., mental health services, family counseling and camps, retreats, peer-based emotional support, military mentoring for children and youth) before, during, and after loss
- Connect all caregiver survivors to relevant, verified grief and bereavement resources, services, and support using proven and trusted processes and platforms (e.g., helplines, case management, seamless referrals, training, webinars, secure online peer groups, community-based meetings) before, during, and after loss
- Conduct research to better understand differences or gaps in the availability or delivery of care and benefits to caregiver survivors related to their veteran's service era, disability rating, status, and/or cause of death
- Advocate for changes in policy, programs, and practices to ensure equitable eligibility for, and access to, care and benefits for all caregiver survivors of service members and veterans regardless of service era, disability rating, status, and/or cause of death

# TAPS ILLNESS LOSS SURVIVOR SURVEY RECOMMENDATIONS

Since 1994, TAPS has provided compassionate care to all those grieving the death of a military or veteran loved one. TAPS is the only organization providing four core services to the bereaved military survivor community: 1) 24/7 National Military Survivor Helpline answered live by caring and compassionate peer professionals, 2) Casework Assistance to support survivors in navigating benefits and entitlements and evaluation of need for emergency financial assistance for urgent concerns not otherwise met by the government, 3) Community Based Care to connect survivors with local mental health professionals for counseling connections; and 4) Peer-Based Emotional Support to connect survivors to others who are further along in their grief journey and share similar experience with the manner of death and the relationship to their deceased loved one.

To identify which of their core or complementary resources and services are most helpful to, and recommended by, specific groups of military and veteran survivors, TAPS regularly solicits feedback from all its survivors. In its analysis of over 8,000 responses to its Survivor Survey in 2021, TAPS found that military and veteran survivors most frequently requested the following resources and services:

- Peer support for bereaved survivors
- Information on programs and services specific to the military-bereaved community
- Mental health resources and/or connections to mental health professionals
- Emergency financial assistance

The following programs, resources, and services were identified as most helpful to, and recommended by, TAPS survivor survey respondents:

- **Programs that connect military and veteran survivors in similar groups**
  - Relationship to deceased (e.g., family or friend)
  - Manner of death (e.g., suicide, toxic exposure illness)
  - Generation (e.g., age of caregiver survivor)
  - Specific challenges (e.g., grieving parents of grieving children)
- **Resources on topics to normalize the grief experience**
  - Trauma and loss (e.g., sudden and suicide)
  - Mental health (e.g., sleep, anxiety, and medication)
  - Navigating life with a broken heart
  - Specific challenges (e.g., parenting grieving children)
- **Services offering tangible and practical tools**

- Managing money and legal issues
- Building strong family bonds while grieving
- Developing coping skills for all generations

Findings and recommendations from this analysis provided TAPS with information that is being used to increase and enhance both their online and in-person peer support resources and services to meet the needs of all military and veteran survivors. Based on survivor survey feedback, TAPS plans to expand financial assistance to parents of minor children and to offer more peer support groups for parents and youth.

## C2S FOCUS GROUP RECOMMENDATIONS

The recommendations from the C2S Focus groups aligned with major areas identified in the seminal Hidden Heroes: America's Military Caregivers report<sup>1</sup> from 2014. Not surprisingly, in 2021 the recommendations from the C2S focus groups aligned with these four areas:

### EMPOWER CAREGIVERS

**Provide potential caregiver survivors with timely and clear information, explanations, and training to help them plan for their role and responsibilities before and after loss of their loved one**

- Develop, implement, and sustain employment support, retraining, and educational support programs for caregivers and caregiver survivors
- Develop, implement, and sustain caregiver competency education for people working in sectors where they may interact with the caregiver community
- Develop a checklist to help with funeral preparations, legal assistance, and support for current and former service members, their families, and caregivers

This recommendation is consistent with that of the Hidden Heroes report which requested that innovations in training for caregivers be included in services provided both online and in person to help them meet their information and skills needs.

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<sup>1</sup> Ramchand, Hidden Heroes.

## CREATE INCLUSIVE, CAREGIVER AND SURVIVOR-FRIENDLY ENVIRONMENTS

### **Offer caregivers and caregiver survivors the affiliation with others—with peers who share(d) their experience**

- Refer caregiver survivors to programs where others with similar lived experience caring for, and losing, a veteran can share helpful resources and services
- Provide awareness of, and access to, others with relevant bereavement experience to increase the likelihood of finding peer support sooner in the journey
- Create more in-person and virtual opportunities for bereaved caregiver survivors to share with peers in confidence

## FILL GAPS IN PROGRAMS AND SERVICES TO MEET NEEDS

### **Increase awareness of, and eligibility for, resources and services available to caregiver survivors of illness and suicide loss**

- Include relevant information on criteria that might distinguish, or limit, survivor access to government assistance (e.g., burial, pension, education benefits)
- Support those grieving a loved one who has died from toxic-exposure-related illness or suicide with relevant information on all care (including mental health) and benefits, and assist them to access and navigate all needed resources and services

### **Increase awareness of, and access to, the full range of relevant bereavement resources and services**

- **Develop, implement, and sustain programs focused on increased case management** for the purposes of organizational, resource, and benefit navigation for caregiver survivors including assistance with completing applications which is critical to obtaining benefits and resources
- **Provide anticipatory grief support and preparation for the death of a loved one** for current caregivers and their children as they experience the transition from caregiver to survivor
- **Streamline access and allocate resources to mental health and grief counselors** to support caregivers and caregiver survivors

This C2S focus group recommendation is consistent with that of the International Alliance of Carer Organizations 2021 Global State of Caring report<sup>2</sup> which identified the need for more information and knowledge to enable carers to access resources appropriate to their needs and the stage of their journey.

**Connect all caregiver survivors to relevant, verified bereavement support interventions, resources, and services**

- **Identify and normalize caregiver survivor challenges across the bereavement journey** by ensuring they have access to other caregiver survivors as peers and mentors through various virtual and in-person venues
- **Allocate resources to develop, implement, and sustain childcare programs** that will benefit caregivers and all caregiver survivors. Access to childcare is of particular importance so they can attend mental healthcare and grief support appointments and resource services, a critical component of the caregiver-to-survivor healing and support journey.
- **Offer assessment and age-relevant support, including mentorships, to children in caregiving homes who are experiencing anticipatory grief or who have experienced a loss**

Appendix E includes a list of the resources and service groups the C2S focus groups identified as helpful.

## PLAN EARLY FOR THE FUTURE

**Assess the care receiver and all caregiver needs**

- **Develop and sustain programs that foster financial, legal, and end-of-life planning**

This recommendation is consistent with that of the Hidden Heroes report which acknowledged the need for caregivers to have assistance in creating financial and legal plans to ensure not only the well-being of their care receiver but also of themselves.

**Create a customized, comprehensive, evolving support plan for the care receiver and all caregivers** to address the full range of their current and future care and support needs

- **Allocate resources for program development, implementation, and sustainment** to address critical mental healthcare needs for children providing caregiver assistance

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<sup>2</sup> International Alliance of Carer Organizations, Global State of Caring.

- **Develop, implement, and sustain programs focused on resources for 24-hour homecare services and caregiver respite resources and services**

Caregivers participating in the Choose Home Initiative reported high levels of engagement and communication with care coordinators and more comprehensive services. Providers in the initiative reported that streamlined workflows made referral and consult processes easier and reduced staff burden which benefited both the veteran and the caregiver.

**Develop multiple options for accessing information to help prepare for loss** (e.g., checklist, quick start guides, webinars, remote support groups) by identifying and assisting with legal needs, financial benefits, and funeral and memorial planning both before and after death.

- **Ensure surviving caregivers understand the full range of services and support available to them** whether they choose to use the VA's National Cemetery Administration (NCA) services or those in the community, including their access to the VBA Office of Survivor Assistance (OSA) services

Caregiver survivors consistently remarked on the challenges they faced after their loved one's death due to lack of information and readiness for the potential, or eventuality, of loss. Having a greater awareness of, and assistance with, the legal and financial changes due to the death of a service member or veteran would have helped reduce at least some of the challenges during their grief.

**Help with comprehensive planning in advance of loss for changes** (e.g., legal, financial, health care, etc.) to better prepare caregivers for their transition to the role of survivor following their loved one's death

- **Amend the current VA VHA Integrated Case Management Standards of Practice** by including "end-of-life care" in the case management process when requested by the family or caregiver.
- **Offer timely, culturally sensitive, and supportive explanations of changes in health condition** and transitions to palliative and hospice care and options for home-based and facility-based end-of-life care.

*"Being included in the medical team review was very nice and respectful. Some providers were seen to be good while others were condescending."— Post-9/11 caregiver survivor*



## LITERATURE REVIEW, RESEARCH, AND STUDIES RECOMMENDATIONS—SUMMARY

- Fill research gaps on the experience of military and veteran loss; sudden loss (e.g., accidents, COVID); suicide loss; families, children and youth; diverse groups; and peer and group support.
- Collect more evidence on the impact of bereavement interventions for military and veteran loss; sudden loss (e.g., accidents, COVID); suicide loss; families, children, and youth; diverse groups; and peer and group support.
- Incorporate Human-Centered Design (HCD) in the regular and systematic collection of both qualitative and quantitative data on the veteran caregiver survivor experience
- Create more customized interventions to better address the unique context, circumstances, culture, and needs of bereaved caregiver survivors
- Conduct more assessments (e.g., quantitative, symptoms) to measure the impact and outcomes of bereavement interventions
- Systematically connect interventions for peer grief support after suicide (PGSS)

## THE ELIZABETH DOLE CENTER OF EXCELLENCE FOR VETERAN AND CAREGIVER RESEARCH RECOMMENDATIONS

The Center’s literature and research review identified the lack of studies on the experience of military and veteran caregiver survivors as an issue that needs to be addressed. This gap in knowledge was also noted in the RAISE Task Force report which studied the civilian caregiver population.<sup>3</sup> Both the Center and the Task Force identified the need for improvements in the quality and consistency of research and data collection to better support these populations.

***In addition to the need for more, and more specific, research on the experience of military and veteran caregivers and caregiver survivors, the Center identified a major opportunity to support VA in “reframing its overall approach to care” from one that includes not only end-of-life care for the veteran but also next-phase-of-life care for survivors.***

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<sup>3</sup> RAISE Family Caregivers Act Initial Report.

The Center recommended more closely integrating the design and implementation of research in the context of the VA's larger customer and patient experience model where the customer is not only the veteran, family, caregiver, and survivors but the employee providing the full range of administrative support and clinical care services. The VA is perfectly suited for this approach given its existing leadership in research and studies and its daily delivery of the full range of care and services to the most diverse population through the largest integrated health care system in America.

With its specialized focus on the veteran and caregiver, the Center can help integrate relevant research from across the VA and other stakeholders. By applying the VA's enterprise-wide commitment to customer experience (CX), the Center can ensure research findings become integrated into the VA's innovation and delivery of high-quality care.

This approach will allow the VA to continue its leadership in addressing caregiver and caregiver survivor needs by more adeptly supporting the growing numbers of aging, ill, and injured veterans and their families, caregivers, and survivors in a more informed and responsive manner across their entire journey, including in the critical journey of loss and grief.

## RESEARCH APPROACH

The Center recommends a two-phased approach to research and its implementation to allow for the rapid dissemination of knowledge into the delivery of routine care.

### **1. Expand our knowledge of survivors' needs and preferences regarding support. Determine how best to integrate this expanded knowledge into routine clinical care.**

Incorporate a human-centered design approach to understanding the needs and preferences of veterans, caregivers, survivors, front-line clinicians, and program offices. Address key information gaps:

- How do we support caregiver to survivors' unique needs in a comprehensive manner?
  - How do we better match interventions to survivors' unique needs and circumstances?
  - How do we best support veteran/survivor dyads, and survivor family systems?
  - How can we best support survivors of sudden loss?
- How should we adapt interventions to meet caregiver to survivors' cultural needs?
  - How do we most effectively include the LGBTQ+ community?
- What outcomes best reflect caregivers to survivors' needs and priorities?
- At what points in veterans' care should caregiver and survivor support be integrated?

- What support can veterans' clinical staff provide?

## **2. Develop and pilot interventions that address deficits in current survivor support giving key consideration to:**

- How do we tailor interventions to meet the needs of caregiver survivors and their families?
  - How can we support emotional and practical “whole-person” and “family unit” needs?
- What is the best strategy to evaluate interventions based on the needs and moments that matter to individuals and families across their caregiving experience?
- How do we effectively partner with community organizations and state entities?
  - How do we integrate peer, faith, and community resources into caregiver to survivor support?
- How do we best equip front-line clinicians to support caregivers on their journeys to survivors?

The Center's approach can use research from multiple sources to expand knowledge of survivors' needs and their preferences for support. The recommendations of the two previously-referenced, systematic suicide studies<sup>4,5</sup> could contribute to the Center's rapid implementation of service-delivery improvements to caregiver survivors who need to access not only benefits assistance but expanded postvention services for grief and bereavement support after the loss of their veteran, including from suicide, by:

- Organizing research from the bottom up by involving survivors and peer helpers as partners in the design, execution, interpretation, and dissemination of research studies
- Increasing the capacity for offering peer-to-peer support services as a key component of suicide bereavement care and support
- Using integrated suicide grief support programs such as TAPS to serve the large, growing, and discrete population of survivors bereaved by the suicide of a military or veteran loved one

## RESEARCH APPLICATION

The Center's recommendations for changes in the approach to research were reinforced by the feedback from survey and focus group participants. Their comments highlighted the need for research to be applied in real time to ensure processes and providers are best prepared to help caregiver survivors when and how they need it most before, during, and after a veteran's death.

Building on the current customer experience (CX) focus of the VA, the Center's research will be applied to

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<sup>4</sup> Bartone, “Peer Support Services.”

<sup>5</sup> Cook et al, “Evidence- and Practice-Informed Approach.”

inform interventions, resources, and services offered by the VA, other government agencies, VA-referred or affiliated private providers, and/or veteran service, non-profit, community, and faith-based organizations.

A major strength of VA research is its connection implementation. An approach to research that involves clinicians and other health care providers in design and execution, and then applies findings to service delivery, can significantly improve the overall experience of veterans, caregivers, and caregiver survivors. An example of this more “patient-centric and informed” approach to research is the Choose Home Initiative whose findings and recommendations are relevant to the Center’s emphasis on the application of findings in care delivery.

Veterans, caregivers, and caregiver survivors consistently request additional resources to support care in non-institutional settings. Service members, veterans, and their caregivers report being happier and more comfortable when they remain in their own homes while receiving care.<sup>6</sup> The report<sup>7</sup> of the Department of Veterans Affairs’ Choose Home Initiative of 2019 offered relevant suggestions for systematically improving veterans’ care plans by including caregivers; integrating the vast array of supportive in-home and community-based services; and streamlining the processes by which eligible veterans are identified, enrolled, and their care is managed. They recommended the VA:

- **Prioritize development and deployment of standardized, objective, and comprehensive assessment tools** to ensure that the health, mental health, and care assistance and respite needs are identified and can be addressed and include information on the need for social, emotional support of both the veteran and the caregiver(s).
- **Meet the need for customized care plans that also include the health and welfare of caregivers** and enable them to better prepare for their role as an end-of-life caregiver and caregiver survivor by offering alternatives to the multiple program-specific/locally-defined assessments.

*“We’ve had a recent discussion with our Caregiver Support Coordinator around a [telehealth] session they conducted with the veteran in his home. The daughter was out of state but very heavily invested in her father’s care. It was a three-way video conference and she said it was awesome.”—Butler VAMC, Butler, PA pilot site*

- **Systematically capture information on the needs of those veterans and their families, caregivers, and survivors most at risk** (e.g., Complex Care, SCI, Polytrauma) or underserved (e.g., rural, minority, LGBTQ+) in conjunction with specialty services such as geriatric, palliative, and hospice

6 Julie Leftwich Beales, Thomas Edes, “Veteran’s Affairs Home Based Primary Care.” Clinics in Geriatric Medicine, February 25, 2009; Volume 25, issue 1, P149–54, viii–ix, <https://pubmed.ncbi.nlm.nih.gov/19217499/>.  
[https://www.geriatric.theclinics.com/article/S0749-0690\(08\)00068-2/fulltext](https://www.geriatric.theclinics.com/article/S0749-0690(08)00068-2/fulltext).

7 Department of Veterans Affairs’ Choose Home Initiative report.

care to improve the delivery of services for veterans and caregivers across their journey

- **Identify gaps in resourcing for special populations** of veterans at risk or underserved to develop enterprise-wide Choose Home strategic plans for meeting the highest risk subgroups with options to address their unique needs
- **Ensure greater access to high need services not available within the VA** portfolio of care and programs across the entire caregiver to survivor journey by identifying community partnerships and needed agreements to integrate their services with existing care

To ensure that veterans and caregivers have access to services not available within the VA, the Choose Home Initiative also recommended identifying needed community-care partnerships and integrating their services more closely into care plans. The Center's approach to the rapid deployment of research findings to improve the delivery of clinical care would support the VA's ability to do this.

## ACTIONS OF THE CAREGIVER TO SURVIVOR (C2S) PARTNERS

### C2S PARTNER ACTIONS—SUMMARY

#### **Research**

- TAPS will lead, and disseminate, information on research on bereaved survivors—including caregiver and suicide survivors—to help the C2S Partners and other stakeholders increase their understanding of the moments that matter most to them and improve the collaborative delivery of care, benefits, resources, and services.
- EDF will continue to make investments in and advocate for increased research to understand the needs facing caregiver survivors. Leveraging its online communities, and opportunities for in-person and virtual programming, EDF will also facilitate and host discussions with the caregiving community around emerging needs as it relates to advance care planning.

#### **Referrals**

- TAPS, Red Cross MVCN, and EDF will share their enhanced, standardized process for referrals and associated data with relevant stakeholders. The new process is currently ensuring a more expedited, seamless, and accountable process for self and “warm” referrals of caregiver survivors to, and between, the three organizations. The process is supported by data collection and analysis that allow the identification of trends and needed resources.
- TAPS will lead the collaboration of Gold Star and community-based organizations to help the Department of Veteran Affairs (VA) pilot a Gold Coat Program which will train volunteer peers to offer caregivers and survivors supplementary support including information on resources and services and navigation assistance before and after the death of their loved one.

#### **Resources and Services**

- Red Cross MVCN is hosting a new inventory of verified resources and services for caregivers anticipating, and caregiver survivors experiencing, bereavement on the Red Cross Hero Care Resources Directory platform <https://www.redcross.org/herocareresources>. This dedicated web-based search tab contains content specifically responsive to the needs of military and veteran caregivers and caregiver survivors. It will help individuals, organizations, and agencies find and utilize more verified and relevant resources and services. This information has been shared with the National Resource Directory (NRD) and Code of Support Patriot Link and will be available to other stakeholders.
- EDF will leverage its Hidden Helpers Coalition to disseminate resources and programming for children and youth as it relates to grief support, advance care planning, and mental wellness resources.

### **Readiness and Training**

- TAPS will offer new Grief and Bereavement Training for caregiver survivors, peer supporters, mentors, and professionals through the TAPS Institute for Hope and Healing® to increase awareness of the grief process, the experiences of the journey, and the benefits of bereavement support for caregiver and suicide survivors of all ages. <https://www.taps.org/institute>.
- MVCN will offer additional Caregiver Education to include webinars and virtual engagements such as texts and chats. These will be recorded in an online library and will include training to provide education for practical skills on how to care for a loved one and whole health opportunities. <https://www.redcross.org/get-help/military-families/services-for-veterans/military-veteran-caregiver-network.html>
- EDF will also expand its information and offerings of training and CEUs to health care providers through its Academy for Inclusive Care and create new financial resources for caregivers to better navigate financial challenges and secure their financial future. <https://campaignforinclusivecare.elizabethdolefoundation.org/academy-for-inclusive-care/>.

### **Recommendations and Advocacy**

- TAPS will advocate before the legislative and executive branch agencies along with the military and veteran community to share the input of caregiver survivors for greater clarity in benefits eligibility, more support for illness and toxic exposure, more and quicker access to mental health services and peer support, and additional comprehensive services for loss from suicide.
- EDF will expand the content of its successful public campaigns to raise awareness of the experience of caregivers of all ages who become survivors and its advocacy for greater understanding and support for their needs.
- MVCN will collaborate in its effective community-based communications across the country to help address the requests of caregiver survivors for assistance with resources and services along their bereavement journey.

The C2S Partners have collectively and individually committed to take the following actions based on the experience of their respective organizations, the feedback from caregivers and caregiver survivors, and the findings of the literature and research.

**These actions reinforce the groundbreaking recommendations of the Hidden Heroes report<sup>1</sup> and are consistent with the recommendations of more recent studies including the landmark 2017 National Guidelines on Responding to Grief, Trauma, and Distress After a Suicide,<sup>2</sup> the 2019 Choose Home Initiative report,<sup>3</sup> and the 2021 RAISE Task Force report.<sup>4</sup>**

## RESEARCH

To help address the research recommendation of the Center, the C2S Partners will address the need to build the capacity among themselves and the larger stakeholder community to capture, analyze, and share data on:

- **Caregiver survivors and their needs at key moments that matter across their journey**, including how they anticipate, navigate, and live through their journey of giving care into and through their journey of surviving loss and grief
- **Interventions, resources, and services offered to the veteran caregiver survivor** to meet those needs by the VA, other government agencies, VA-referred or affiliated private providers, and/or veteran service, non-profit, community, and faith-based organizations
- **Outcomes of interventions using common metrics to support both services recovery and program improvement efforts**, to help validate and identify interventions with the most beneficial impact and to identify gaps in current resources and services from all stakeholders

**EDF** will continue its leadership role in caregiver research and fill a key gap in our understanding of how caregivers' needs change over time. This entails recognition of an aging veteran—and caregiver—population, for whom planning and preparing oneself for loss is a vital need.

EDF will also expand its information and offerings of training and CEUs to health care providers through its Academy for Inclusive Care and create new financial resources for caregivers to better navigate financial challenges and secure their financial future. <https://campaignforinclusivecare.elizabethdolefoundation.org/academy-for-inclusive-care/>

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1 Ramchand, Hidden Heroes.

2 Survivors of Suicide Loss Task Force, Responding to Grief, Trauma, and Distress

3 Department of Veterans Affairs' Choose Home Initiative report.

4 RAISE Family Caregivers Act Initial Report.



**TAPS** will launch a fourth version of the survey to over 40,000 adult military survivors to identify which survivors served as a caregiver prior to becoming a survivor. From this survey, TAPS will be able to report on caregiver survivors in relation to the manner of death and other demographics. Other results will include a more accurate representation of how many survivors identify as a caregiver survivor, how many caregiver to survivor households include(d) school-age children, and the most requested services for grief and trauma. TAPS will apply this understanding of trends and challenges to its own ongoing support for survivors of all relationships, manners of death, and ages. It will also share this information with stakeholders to enable them to make more knowledgeable decisions on policy, programs, and practices to best address the full range of resource and service needs of caregiver survivors along their bereavement journey.

**The voluntary collection, analysis, and sharing of actionable information—with appropriate privacy protection protocols, shared definitions, and some common metrics—across the stakeholder community will enhance the ability of researchers and resource and service providers to identify trends and meet the needs and challenges that caregivers and caregiver survivors experience over time.**

The movement toward the systematic collection of data from multiple channels (e.g., surveys, focus groups, chats, controlled studies) to facilitate the ability of stakeholders to collaboratively listen, learn from, and respond to the needs of caregivers and caregiver survivors will be a significant contribution of the C2S Partnership.

This will improve the common commitment of the C2S Partners and other stakeholders to better address the entire journey—including bereavement—of these populations. It will offer more opportunity for informed action and accountability by providing them with the full range of resources and service to help caregiver survivors navigate their caregiving and find their new path forward as their journey continues after loss.

## REFERRALS

**TAPS, Red Cross MVCN, and EDF** implemented a streamlined and more accountable process for self-referral, inter-organizational referrals, and case management. This new standardized process is collecting helpful information and documents digitally. It is allowing the partner organizations and caregiver survivors to select the types of support, resources, and services needed at a particular point in time and enabling organizations to be more prepared to respond in a timely and relevant manner.

It is also providing the organizations with a record of caregiver survivors supported, and the assistance offered to them for an inventory of utilized resources and services, and for program evaluation and improvement.

This new process, initially supporting the expedited and personalized “warm referral” of caregiver survivors to TAPS for all causes of loss, is enabling the C2S Partnership to collect demographic information that can help spot trends in loss and needs. Measures are being phased in to track metrics, ensure responsiveness, and evaluate the experience. This data is being used to help the C2S Partners better prepare caregivers for loss, support survivors in their bereavement, and improve access to needed resources and services among the caregiver survivor community. The new referral process will be shared for use by other stakeholders referring individuals for bereavement services.

## RESOURCES AND SERVICES

**Red Cross MVCN** led the effort to ensure the identification, verification, and publication of clear and accessible information on resources and services specifically relevant to the moments that matter, and challenges experienced by military and veteran caregivers and caregiver survivors along their bereavement journey.

A new, dedicated, web-based search tab on <https://www.redcross.org/herocareresources> now provides one location where military and veteran caregivers, caregiver survivors, survivors, and those who support them can access information on verified information and assistance specifically identified to address their unique needs.

Red Cross MVCN information is also accessible from the app under Caregiver Services and Caregiver Services Resources tab including full access to the Hero Care Resource Directory. The Network will share its tab not only with the C2S Partner organizations, the VA, and all stakeholders, but also with other services like the National Resources Directory (NRD), FindHelp.org, and Patriot Link.

This action not only addresses the requests and recommendations of the C2S focus group participants, but it fulfills an original recommendation of caregivers in the Hidden Heroes report<sup>5</sup> who asked that consolidated platforms, like the National Resource Directory (NRD), be up to date with relevant information that reduces their challenges of navigation when searching for help. This adaptable caregiver to survivor resources and services tab will not only be accessible through the NRD but will be shared widely with other stakeholders to ensure widespread access and utilization by both caregiver survivors and those who assist them.

This action also helps fulfill one of the primary goals of the VA’s Choose Home Initiative which was to incorporate more community-based services into care plans and improve access to these resources. The

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<sup>5</sup> Ramchand, Hidden Heroes.

new caregiver survivor search tab in the Hero Care Network has incorporated the relevant VA and external stakeholder tools for veterans, caregivers, families, and survivors in their communities collected in the Choose Home Initiative. Its electronic access will help the VA and all stakeholders improve two-way access between their use of the VA and community-based services.

**TAPS** will lead the C2S Partners in delivering a full range of free and unlimited comprehensive bereavement programs and services (e.g., 24/7 helpline, case management, benefits information and eligibility assistance, educational assistance, online and in-person peer support, military mentors, survivor events and retreats, training webinars, connections to professional mental health support, etc.) to military-connected caregiver survivors of all ages. They will collaboratively connect those in grief with additional resources identified as beneficial in the Hero Care Network platform.

Because early interventions of bereavement and peer support are helpful for caregiver survivors of all ages, TAPS is expanding its in-person family camps and offering monthly virtual parenting groups where parents, grandparents, and caregivers raising grieving children can come together to learn strategies for supporting their children and teenagers. This will include opportunities for children and youth to affiliate with other peers (e.g., other suicide survivors) and to benefit from the mentorship of a non-family adult (e.g., military service member) who can provide the attention and positive conditions of affirmation they so need when experiencing loss or during grief. TAPS will also pilot TAPS Child and Teen Care Groups to offer monthly peer support gatherings in local communities in conjunction with TAPS adult care groups. This will offer them in-person connections which are especially helpful for those who have been Hidden Helpers or have experienced suicide loss.

**EDF's** Hidden Helpers Coalition will offer support and guidance for family members, including developmentally appropriate resources and support for children and youth. Materials will be made available for children and parents on EDF's forthcoming Family Resource Hub. Webinars will be offered featuring experts on grief and children to provide guidance to family members.

Elizabeth Dole Fellows will be supported through the caregiver navigator program to fund small community events on the issues (legal, financial, and emotional) on the journey from caregiver to survivor.

In addressing mental wellness issues, EDF is sponsoring small group sessions (8 weeks) for caregivers to share their feelings and thoughts in a supportive environment.

## READINESS AND TRAINING

- **TAPS** is designing new grief and bereavement training for survivors, professionals, and peer supporters through the TAPS Institute for Hope and Healing® with collaboration from the C2S Partners and others.
- **Red Cross MVCN** plans to soon offer caregiver education to include webinars and virtual engagements such as texts and chats and add them to their online library. *The Family Caregiver Training Course*, for example, could provide practical skills training on how to care for a loved one. MVCN will also be adding a training module for all volunteer caregiver peer supporters to better support the caregiver to survivor journey.
- **EDF** will offer caregiver professionals and clinical providers information and CEU credits on the experience of caregivers as they prepare for and transition to the role of survivor through its *Academy for Inclusive Care*.

## RECOMMENDATIONS AND ADVOCACY

**TAPS** is using the information from the bereaved military and veteran caregiver survivors and the research, surveys, and focus groups to inform its priorities for advocacy on behalf of the needs of survivors of a visible or invisible illness or injury associated with military service, chronic illness, COVID, and/or sudden loss and suicide. TAPS is collaborating with the C2S Partners and other stakeholder organizations in their work with the legislative and executive branch agencies to address near-term priorities including:

- **Reducing the confusion of eligibility for benefits and improving the efficiency of service access and delivery for all survivors of a military death by establishing a standard definition in statute for Gold Star Families**

The VA does not determine eligibility for services based on the type or cause of death. There is no differentiation in the placement of cemetery headstones, the offer of a folded flag, or entitlement to government benefits based on the circumstances of death for the service member (e.g., death from a combat injury or a cancer illness connected to toxic exposure).

- **Recognizing illness and toxic exposure caregivers and caregiver survivors**

TAPS, as the co-chair of the Toxic Exposure in the American Military (TEAM) Coalition, is helping ensure veterans get immediate and lifelong access to VA health care and that their caregivers and caregiver survivors receive the assistance and support they need and deserve.

- **Reducing the stigma for all survivors and increasing access to mental health services including peer support**

TAPS continues to work with the VA, DOD, and Congress to expand mental health services to all surviving families, and to increase suicide prevention and postvention efforts among active-duty service members, veterans, their families, caregivers, and survivors. Vet Centers are seen as one source for improving access to critical services for veterans, families, caregivers, and survivors.

**EDF** will add to its successful public campaigns to raise awareness of the experience of caregivers of all ages who become survivors and its advocacy for greater understanding and support for their needs.

- **Offering Online Education**

EDF will continue to offer webinars on financial planning, including discussions led by experts on estate planning and budgeting. These webinars are for caregivers and led by EDF's financial wellness team.

- **Advocate for Families**

EDF will continue to work closely with its partners, TAPS and MCVN, to ensure that caregivers and their families are supported throughout their caregiver journey, including the role of survivor. The needs of caregiving families are immense and include managing VA benefits, legal and financial issues, as well as grief, acceptance, and moving on.

- **Convene New Partners**

Recognizing the groundbreaking work of TAPS in supporting military and caregiving families on loss, including sudden loss, and anticipatory grief, it is incumbent that the caregiver ecosystem work in partnership to ensure that no family is left behind after the loss of their loved one. Together with TAPS and MCVN, EDF will explore new partnership opportunities to expand the current landscape of benefits, programs, and services available to military and veteran caregivers, and survivors.

**MVCN** will broaden its effective community-based communications across the country to help address the requests of caregiver survivors for assistance with resources and services along their bereavement journey including:

- **Advocating for caregiver skills trainings**

A comprehensive caregiver task training that could support mental health and end-of-life care with all the practical skills needed to help with activities of daily living for the care recipient.

- **Adding C2S caregiver peer support training to the curriculum for MVCN volunteers**

This will be an additional offering to all caregiver peer supporters providing them knowledge of the referral process and resources available for the bereavement journey.

- **Providing a custom, secure online community with a group dedicated to peer support needs of caregivers dealing with ambiguous and anticipatory grief**

MVCN will leverage partnerships to share meaningful content for caregiver survivors and those who serve them.

## CHAPTER SIX

# SUMMARY

***The pandemic of bereavement has touched our nation, and military and veteran caregivers and caregiver survivors, in significant and lasting ways. Many have had to manage a tsunami of grief from separations, debilitation, and deaths from COVID, service-connected illness, and the trauma of sudden and suicide loss.***

These overwhelming challenges needed to be more fully understood before a full, respectful, and relevant response of help could be offered to the growing number of military and veteran caregiver survivors. The C2S Partners listened closely and intentionally to the moments that mattered most to them before, during, and after their loved one's death. They heard that:

- **Confusion and chaos are common and often overwhelming and depleting.**
- **Loss and grief occur before, during, and after death.**
- **Access to the right resources and services at the right time can prevent and mitigate the greatest challenges and worst consequences.**
- **Children and youth are significantly and lastingly touched by losses.**
- **Early interventions of bereavement and peer support are helpful for survivors of all ages.**

The C2S Partners are leaning in with specific actions to meet their continued commitment to caregivers and caregiver survivors and to work even more closely with other stakeholders. By sharing the feedback from surveys and focus groups and the information from research and studies, they hope all who serve military and veteran caregivers and caregiver survivors can be better equipped to identify and deliver needed resources, services, and support.

*“By listening and leaning in together, we can prevent the often-debilitating, long-term consequences of prolonged grief for caregivers, caregiver survivors and for their families along their journey of loving, caring, losing, grieving, and living on.”*

—Lynda C. Davis, Ph.D., Former Chief Veterans Experience Officer, US Department of Veterans Affairs

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## APPENDIX A. MOMENTS THAT MATTERED TO CAREGIVER SURVIVORS

### **Key Moments that Mattered to Caregiver Survivors**

- Lack of preparation for the ever-changing role(s) of caregiver and caregiver survivor is a constant challenge.
  - Juggling multiple caregiving roles simultaneously is overwhelming.
  - Identifying and accessing needed information, resources, services, and support—before, during, and after their loved one’s death—is too complicated.
  - Planning for, and meeting, legal and financial requirements of caregiving and as a caregiver survivor is demanding.
  - Coping with the mental health struggles, addressing resistance and stigmas, finding services and processing grief before, during, and after their loved one’s death, was a constant challenge that has significant consequences.
  - Securing emotional support for anticipatory, complex, traumatic grief, and bereavement—before during and after their loved one’s death—was often left to chance.
- 

### **Additional Moments that Mattered to Caregiver Survivors**

- Sacrificing careers and education to perform caregiving duties resulted in loss of income and future earning potential.
- Failure to see themselves as a caregiver if their veteran had “invisible wounds” like PTS/PTSD limited their understanding.
- Differences in services available to veterans, caregivers, and caregiver survivors by era of service can make it hard to find assistance.
- Opportunity to guide other caregivers and caregiver survivors as peers and mentors after having time to process their own loss.
- Navigating and interacting with multiple systems of care was difficult.
- Lack of support and resources for non-spouse caregivers (e.g., parents, siblings) made it challenging.
- Struggles with the grieving process after death were compounded by being lost without the caregiving duties.
- Frustrations filling out multiple forms and repeatedly needing to discuss their finances with different advisors to access services were often mentioned.



- Experiencing unexpected separations and isolation while caregiving and at death—whether due to the quarantine of the pandemic or the unexpected loss by a suicide—causes additional pain.
- Appreciation for the value of peer grief support—especially for the sudden loss of suicide—was expressed by all caregiver survivors who had access to it.

## APPENDIX B. REVIEW OF THE MOST RELEVANT BEREAVEMENT LITERATURE AND RESEARCH BY THE CENTER OF EXCELLENCE FOR VETERAN AND CAREGIVER RESEARCH

<b>Study</b>	<b>Topic</b>	<b>Key Findings</b>	<b>Research Gaps</b>	<b>Future Research Direction</b>
Bartone 2017	Peer support	Peer support has positive impacts on grief and growth.	Not all included studies were RCTs	Internet-based support  Higher-quality evidence
Gomes 2013	Home palliative services	Increased odds of dying at home  Decreased symptom burden  No effect on survivor grief	Effect of interventions to improve physical/ psychological health of caregivers of terminally ill patients  Insufficient evidence re: home palliative care on dying at home	Cost-effectiveness  Assessing place of death  Assessing outcomes more sensitive to change  Comparing models of home palliative care  Higher-quality studies
Moss 2021	Bereavement interventions to support caregivers of ICU patients	No positive impact of presence at brain death, condolence letters, storytelling on survivors	Map bereavement interventions to appropriate outcomes  Interventions that improve ability to cope	Understanding what interventions are most effective, for whom, at what time, and in which contexts

Sakinofsky 2007	Bereavement support for suicide survivors, complicated grief	Manualized complicated grief therapy (CBT) is promising  Groups may be effective for children	Improved suicide prevention approaches, particularly for high-risk persons who present in healthcare settings	Developing interventions that include population-based and high-risk approaches must be developed
Wilson 2017	Psychosocial interventions to reduce grief in family caregivers of persons with dementia	Cognitive and behavioral interventions have positive impact	Insufficient evidence regarding grief interventions for family caregivers of persons with dementia	Tailoring interventions to survivors' unique situations  Evaluating impact of complicated grief  Longer follow-up  Measuring effects of post-death interventions  Testing individual components of multi- component interventions

Recognizing that the bereavement journey does not consist of discrete steps, the Center organized their summary of the published literature into the pre-bereavement/post-bereavement phases to show where the evidence is clustered.

APPENDIX C. REVIEW OF THE MOST RELEVANT PRE-BEREAVEMENT LITERATURE AND RESEARCH BY THE CENTER OF EXCELLENCE FOR VETERAN AND CAREGIVER RESEARCH

<b>Intervention</b>	<b>Target</b>	<b>Condition</b>	<b>Assessment Approach</b>	<b>Outcomes</b>
<p><b>Complicated Grief Group Therapy (CGGT)</b></p> <p>Motivational interviewing Cognitive behavioral treatment Prolonged exposure treatment Education normal and complicated grief Guided discussion Structured activities</p> <p><i>Supiano 2017</i></p>	CG	Dementia	<p>120-minute sessions, 16 weeks</p> <p>Therapeutic change in CGGT participants, using an adapted version of the Gillies’ Meaning of Loss Codebook.</p>	<p>Participants demonstrated positive gains in 16 thematic areas, notably in moving on with life, summoning pleasant memories, and ascribing bad memories to disease rather than decedent. Meaning transitioned from negative to positive interpretations of the death over the course of treatment.</p>
<p><b>Therapeutic Conversation Interventions</b></p> <p>Encourage expression of feelings and ideas including active listening, sharing observations, empathy, hope, humor, feelings, using touch, and silence.</p> <p><i>Petursdottir 2020</i></p>	CG	Not specified	<p>Quasi-experimental design, post-test-only comparison to palliative home care services</p>	<p>Decrease in anxiety in the intervention group at three, five, and six months after death</p> <p>Lower controlled grief responses in the intervention group</p>
<p><b>Carer Support Needs Assessment Tool (CSNAT)</b></p> <p>Evidence-based tool used to tailor support for caregivers of adults with long term life-limiting conditions</p> <p><i>Grande 2017</i></p>	CG & CR	Not specified	<p>Mixed method, part-randomized, stepped-wedge cluster trial with six palliative home-care services</p> <p>Caregiver survey four-five months post-bereavement</p>	<p>Achieved preferred place of death, including greater likelihood of dying at home</p> <p>Caregivers in intervention group had significantly lower levels of early grief, better psychological and physical health using SF-12, TRIG, Distress Thermometer</p>

<p><b>Family Focused Grief Therapy</b></p> <p>Family-based interaction begun during palliative care and continued into bereavement for high-risk families</p> <p><i>Betancourt 2014</i></p>	CG & CR	HIV	<p>Twenty families (N=39 children) with at least one HIV-positive caregiver and one child 7–17 years old</p> <p>Six-month follow-up</p>	<p>Improvements in family connectedness, good parenting, social support, and children’s pro-social behavior at six months</p> <p>Improvements in child perseverance/self-esteem, depression, anxiety, irritability</p> <p>Decrease in child-reported harm</p>
<p><b>ENABLE (Educate, Nurture, Advise, Before Life Ends)</b></p> <p>Manualized intervention facilitated by advanced-practice palliative care nurse coaches over the phone</p> <p><i>Dionne-Odom 2015, 2016</i></p>	CG & CR	Cancer	<p>Survey completion 8-12 weeks after death, including:</p> <ul style="list-style-type: none"> <li>• CQOL-C</li> <li>• MCBB Scale</li> <li>• CES-D Scale</li> <li>• ICG</li> </ul>	<p>CGs’ depressive symptoms and complicated grief scores 8-12 weeks after care recipients’ deaths were not statistically different based on the timing of EPC support</p>
<p><b>Meaning-Centered Psychotherapy Inspired Care for the Cancer Caregiver (CCC) Workshop</b></p> <p>Psychotherapeutic intervention intended to augment caregivers’ sense of meaning and purpose and ameliorate burden</p> <p><i>Applebaum 2018</i></p>	CG	Cancer	<p>42 caregivers randomized to CCC</p> <p>FMCS</p> <p>LAP-R</p> <p>Caregiver Reaction Assessment</p> <p>HADS</p> <p>FACIT</p> <p>Benefit-Finding Scale</p>	<p>No pre-post significant differences between groups</p> <p>A longitudinal, mixed-effects model found significant differential increases in benefit in CCC group</p>

<p><b>VOICE (Values and Options in Cancer Care)</b></p> <p>Communication training for oncologists with patients and caregivers coaching</p> <p><i>An 2020 Duberstein 2019</i></p>	<p>CR &amp; CG</p>	<p>Cancer</p>	<p>Caregiver outcomes assessed two and seven months after death.</p>	<p>No improvement in caregivers' PG-13, mental health function, depression, or anxiety</p> <p>Improved purpose-in-life scores</p> <p>Experiences of EoL care were promising, though none were statistically significant</p>
<p><b>Hospice at Home (HAH)</b></p> <p><i>Grande 2017</i></p>	<p>CR</p>		<p>96 informal caregivers of HAH patients were surveyed six weeks post-bereavement about the quality of terminal care</p>	<p>No evidence that Hospice at Home impacted bereavement outcomes</p> <p>Perceived inadequate terminal support and high-symptom severity were associated with worse caregiver bereavement outcomes</p> <p>Home deaths associated with better bereavement response and physical health</p>
<p><b>Peer support</b></p> <p>Systematic review of peer-support for sudden/unexpected death</p> <p><i>Bartone 2017</i></p>	<p>CG</p>	<p>Sudden death</p>	<p>Caregiver and peer support outcomes</p>	<p>Reduced grief symptoms</p> <p>Increased well-being and personal growth</p> <p>Positive meaning</p>

<p><b>TAPS Suicide Postvention Model</b></p> <p>Peer support + clinical care Stabilization—trauma assessment and safety Grief work—new rhythm / relationship formation Post-traumatic growth</p> <p><i>Dooley 2019</i></p>	CG	Suicide in military families	RCTs have not been conducted	<p>Accepted by survivors</p> <p>More contacts with TAPS associated with improved post-traumatic growth and resilience</p>
<p><b>Accelerated Resolution Therapy:</b></p> <p>Novel mind-body therapy treating post-traumatic stress disorder (PTSD), and depression among informal caregivers</p> <p><i>Buck 2020</i></p>	CG	Hospice	<p>ICG</p> <p>PCL-5 and/or Psychiatric Diagnostic Screen Questionnaire PTSD subscale</p> <p>CESD</p>	<p>Decreased PTSD symptoms</p> <p>Results suggests ART presents an effective and less time-intensive intervention for complicated grief in older adults.</p>
<p><b>Existential Behavioural Therapy</b></p> <p>Group psychotherapy comprising six sessions over 22 hours during end-of-life and bereavement Max 10 participants/group</p> <p><i>Fegg 2013</i></p>	CG	Any diagnosis, but in palliative care	<p>BSI subscales</p> <p>SWLS</p> <p>WHOQOL-BREF</p> <p>Helpfulness ratings of specific intervention elements</p>	Positive effects on distress and QOL

**APPENDIX D. FINDINGS FROM LITERATURE REVIEWS, RESEARCH, STUDIES, SURVEYS, AND FOCUS GROUPS**

<b>Findings</b>	<b>COEVCR</b>	<b>Peer Support Studies</b>	<b>TAPS Survey</b>	<b>C2S Focus Groups</b>
<b>Literature Reviews and Research Findings</b>				
Overall research on the bereavement experiences and helpful interventions is limited.	x	x		x
Interventions tend to be narrowly defined but caregiver survivor needs are multi-dimensional.	x	x		x
Interventions tend to target individuals, but family support is needed.	x	x	x	x
Interventions have differential effects depending on the needs and situation.	x	x	x	x
Intervening early tends to have better outcomes.	x	x		x
Intervention outcome measures rely on self-reported measures.	x	x	x	x
Pre-bereavement interventions help	x	x		x
Peer support interventions help—even when remote.		x	x	x
Peer support interventions are especially helpful for suicide survivors.		x	x	x
<b>Surveys and Focus Group Findings</b>				
Lack of preparation for the ever-changing role(s) is a constant challenge.			x	x
Juggling multiple caring roles at one time—without assistance or support—is depleting.			x	x
Identifying and accessing needed information, resources, services, and support is difficult.	x	x	x	x
Planning and meeting legal, financial, and health care needs before and after death often requires assistance.			x	x
Coping with mental health stigmas and finding services for all before and after death is a struggle.		x	x	x
Securing emotional support for loss, grief and bereavement should not be left to chance.		x	x	x

## APPENDIX E. RESOURCES AND SERVICES MENTIONED BY C2S FOCUS GROUPS

Education Resources & Services	Chapter 35 Benefits	Informational Resources & Services	Medical personnel
	Children of Fallen Patriots		Military and Veteran Caregiver Network (MVCN)
	Folded Flag Foundation		No Barriers
	Folds of Honor		Organizations that aid in navigating VA benefits
	Texas Hazelwood Act		Paralyzed Veterans of America (PVA)
Family Resources & Services	Chapter 35 Benefits		Parkinson's Foundation
	Children of Fallen Patriots		Patient advocacy representative
	Folded Flag Foundation		Physician's Desk Reference (PDR)
	Folds of Honor		Social media Caregiver networks
	Gary Sinise Foundation		Tragedy Assistance Program for Survivors (TAPS)
	Hospital personnel		TRICARE
	Texas Hazelwood Act		TRICARE Referral System
	Therapy		Vet Center
	Tuesday's Children	Veterans Affairs (VA)	



Family Resources & Services Continued	Veterans Affairs (VA)	Informational Resources & Services Continued	VA Burn Pit Education	
	Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)		VA Caregiver Support Program	
	Wonders & Worries		VA Directory of Veterans Service Organizations (VSO)	
Financial Resources & Services	AARP		Veterans of Foreign Wars of the US (VFW)	
	Case managers		Veterans with ALS book	
	Casualty Assistance Officer		Visiting nurses services	
	Dependency and Indemnity Compensation (DIC)		Warrior 360	
	Disabled American Veterans (DAV)		Legal Resources & Services	Case managers
	El Paso Feeding Hunger			JAG Office
	Elizabeth Dole Foundation			Yale Law
	Financial planner	Medical Resources & Services	American Legion	
	First Command		Case managers	
	Folded Flag Foundation		Current Medical Diagnosis & Treatment (CMDT)	
	Home Chef		Disabled American Veterans (DAV)	
	Independence Fund		Elizabeth Dole Foundation	
	Military and Veteran Caregiver Network (MVCN)		Emergency Room	
	Operation Home Front		Home health and healthcare programs	
	Semper Fi & America's Fund		Hospice care	
	Social Security Disability Insurance		Hospital	
	Survivor Benefit Plan (SBP)		Injury/Illness-specific hospitals	
	Veterans Affairs (VA)		Medicaid	
	VA Benefits		Medical personnel	
	VA Caregiver Support Program		Physical therapist	
Wounded Warrior Project (WWP)	Physician's Desk Reference (PDR)			
WWP Family Support	TRICARE			

Grief Resources & Services	Community of faith	Medical Resources & Services Continued	Veterans Affairs (VA)
	Community of fellow Caregivers and Caregiver Survivors		VA Benefits
	Dignity Memorial Veteran's Planning Guide		Veterans of Foreign Wars of the US (VFW)
	Family		Visiting nurses services
	GriefShare		Warrior Transition Unit
	Injury/Illness-specific hospitals		Wounded Warrior Project (WWP)
	Tragedy Assistance Program for Survivors (TAPS)		WWP Independence Program
	Tuesday's Children		Mental Health Resources & Services
Home Care Resources & Services	Elizabeth Dole Foundation	Community of fellow Caregivers and Caregiver Survivors	
	Gary Sinise Foundation	Elizabeth Dole Foundation	
	Hidden Heroes	Family	
	Home health and healthcare programs	Gary Sinise Foundation	
	No Barriers	Hospice care	
	Veterans Affairs (VA)	Meditation and Mindfulness	
	VA Homemaker and Home Health Aide Care	Military and Veteran Caregiver Network (MVCN)	
	Wounded Warrior Project (WWP)	Mobile Vet Center (MVC)	
	WWP Independence Program	No Barriers	
Informational Resources & Services	ALS Association	Rosalynn Carter Institute for Caregivers (RCI)	

Informational Resources & Services Continued	American Legion	Mental Health Resources & Services Continued	Semper Fi & America's Fund
	Building Better Caregivers		Support for People with Oral and Head and Neck Cancer (SPOHNC)
	Burn Pits 360		Therapy
	Case managers		Tragedy Assistance Program for Survivors (TAPS)
	Code of Support Foundation		Vet Center
	Community of fellow Caregivers and Caregiver Survivors		Veterans Affairs (VA)
	Current Medical Diagnosis & Treatment (CMDT)		Veteran's One Stop
	Disabled American Veterans (DAV)		Visiting nurses services
	Easter Seals		Wonders & Worries
	Elizabeth Dole Foundation		Wounded Warrior Project (WWP)
	Information sharing community events		WWP Family Support
	Injury/Illness-specific medical books	Transportation Resources & Services	Veteran's Affairs (VA)
	Internet		VA Beneficiary Travel

*Note: There were no Employment Resources & Services or Housing Resources & Services named by focus group participants and thus they are not represented on this table.*

## APPENDIX F. RECOMMENDATIONS FROM LITERATURE REVIEWS, RESEARCH, STUDIES, SURVEYS, AND FOCUS GROUPS

Recommendations	COEVCR	Peer Support Studies	TAPS Survey	CzS Focus Groups
<b>Literature Reviews and Research Recommendations</b>				
Fill research gaps on the experience of: 1. Military and veteran loss 2. Sudden loss (e.g. COVID) and Suicide 3. Families/children/youth, diverse groups, peer, and group support.	x	x		x
Collect more evidence on the impact of interventions on loss, sudden loss, for families including children and youth, diverse groups, and peer support.	x	x		x
Incorporate Human Centered Design (HCD) research model to the regular and systematic collection of both qualitative and quantitative data.	x			
Create and use more customized interventions.	x	x	x	x
Conduct more assessments (e.g., quantitate, symptoms) to measure the impact and outcome of interventions.	x	x		
Systematically connect interventions for Peer Grief Support After Suicide (PGSS).		x	x	
<b>Surveys and Focus Groups Recommendations</b>				
Provide potential caregiver survivors with timely, clear explanations and training.			x	x
Assess the care receiver and all caregivers needs before, during, and after loss.		x		x
Create a customized, comprehensive, evolving support plan for the care receiver and all caregivers to address their needs before, during, and after loss.				x
Ensure access to the full range of relevant bereavement resources and services before, during, and after loss.		x		x
Connect all caregiver survivors to multiple, relevant, bereavement support interventions.		x	x	x

## APPENDIX G. TERMINOLOGY

The C2S Partners used the following definitions for key terms and references:

**“Bereavement”** is the state of being deprived of a person, often a loved one, because of death.

**“Caregiver,”** as defined in the 2014 RAND report, is a family member, friend, or acquaintance who provides care and assistance for, or who manages the care of, a current or former military service member. They help with a wide range of both physical and mental illnesses and injuries.

The 2021 RAISE Task Force Report to Congress defines caregiver in its most inclusive sense to encompass “All unpaid individuals of all ages who are caring for a service member or veteran with illness and/or injuries that result in disabilities, or acute or chronic health conditions, and/or functional limitations.”

This term includes family members (in some families, multiple individuals serve in this role including children and youth), partners, friends, kinship who care for someone regardless of the type of assistance needed. It includes part-time caregivers and full-time caregivers. These caregivers may have a biological (or legal) connection to the person they support or may be part of a “family of choice.” A “family caregiver” is not the same as “next of kin.”

**“Caregiver survivor”** families are those who have lost a military loved one after having been a caregiver, helping navigate a grief journey that may have begun even before the death of a military loved one. The leading cause of death of military survivors is illness, but many experience a loss after having cared for a loved one who was traumatically injured or diseased as well. Many survivors’ loved one’s illness is connected to their service overseas, where they were exposed to burn pits and many other toxic exposures.

Differences in the grief and bereavement journey may present when someone has been a caregiver before they have transitioned to a survivor.

**“Grief”** describes the response to loss and/or death. It is often associated with the deep and poignant mental suffering or emotional distress associated with bereavement. It can include anticipatory grief for the loss of things or relationships that will not be experienced because of illness and/or impending death.

Ambiguous grief may be experienced when a loved one is still physically present but psychologically absent or vice versa.

Anticipatory grief refers to the fear of not being able to experience things or relationships because of loss. It is often associated with changes brought by the loss of a loved one’s health or the ability to participate in

## APPENDIX H. ACKNOWLEDGEMENTS

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