



My Loved One Has Passed Away, Now What?

Former President Abraham Lincoln's credo was, "To care for him who shall have borne the battle and for his widow, and his orphan."

The new, more inclusive motto is still based on Lincoln's words but instead reads, "To fulfill President Lincoln's promise to care for those who have served in our nation's military and for their families, caregivers, and survivors."

The purpose of this presentation is to provide a framework for families, caregivers and survivors of a Veteran. After a Veteran passes, many times their family members are not sure what to do next and how the VA can support them in their time of need. We will discuss the next steps after your Veteran passes away, who to notify, what resources are available and discuss the grieving process.

Everyone listening to this podcast is either a caregiver or has served as a caregiver to someone in the past. In 2023, it was estimated approximately 38 million people in the United States were in the role of a caregiver for a loved one. There are approximately 5.5 million caregivers caring for Veterans, 96% of those caregivers are women, and 70% provide care to a spouse or partner.

The working definition of a primary caregiver is the person who takes responsibility for the care needs of an individual who is unable to care for themselves independently. A caregiver can be a spouse, immediate or extended family member, or a guardian who lives with the individual.

A caregiver may be needed due to various health conditions and disabilities caused by illnesses, injuries and other diagnoses, that may hinder an individual from being able to care for them self. In many cases unfortunately, those illnesses and health situations may lead to the death of a Veteran or loved one and the caregiver is left to pick up the pieces.

Losing someone you love is never easy especially when you are trying to manage your everyday life while grieving. Even though your loved one has passed on, you are still here continuing with your life and adjusting to your new normal. It can be an emotional rollercoaster dealing with everyday stressors while coping with the loss of your loved one. You may also be struggling with how to move forward.

Let's consider how this may play out in everyday life by sharing a story about a Veteran and his spouse after the Veteran passes away. David and Carol were high school sweethearts and were married for nearly 50 years. During their time together,



they enjoyed traveling, being active in their community, volunteering at their church, and spending time with family and friends. Over the years, they created wonderful memories and had a beautiful life together.

David is a Vietnam war era Veteran and awarded a 100% service-connected disability rating. After being honorably discharged from the military, he worked as an auto mechanic until he retired. His favorite hobbies included riding his Harley Davidson motorcycle, restoring a 1969 Mustang, fishing, maintaining his yard, and caring for his two beloved German Shepards. He also frequented his local Veterans of Foreign Wars or VFW post to socialize with other veterans.

Carol continued to work full-time as an office manager for an insurance broker. In her free time, she frequently went on camping and fishing trips with David. Carol would also spend time with her friends meeting them once a week for brunch or hosting dinner parties at their home. Carol had always imagined that she and David would spend their retirement years traveling to exotic places and spending more time with their children and grandchildren.

David and Carol's dream of traveling was realized after booking a seven-day cruise and they were looking forward to a wonderful time exploring the Caribbean and cruise activities. However, to both of their dismay, on the second day of their vacation, David became extremely ill on the cruise and spent the remainder of the trip in the cabin recuperating and resting. David was overcome with guilt and felt he ruined their vacation and encouraged Carol to enjoy the rest of their trip without him.

Carol felt sad that her husband was not feeling well and would therefore miss out on the festivities planned. She was torn about the decision to leave David behind in the cabin and enjoy the rest of the trip without him. Carol decided to stay behind to care for her husband but would occasionally join other passengers for a meal or activity when David was sleeping.

After returning from their trip, David was examined by his primary care doctor at the VA and was diagnosed with congestive heart failure and Stage IV cancer. He required oxygen and was given chemotherapy and radiation treatment. David was always strong and energetic, but after his diagnosis became lethargic, irritable, and disengaged in the activities he used to enjoy.

As David's symptoms worsened and became more complex, the retirement years they dreamt about and hoped for, started to fade away. David increasingly became more dependent on Carol to provide support with his personal care needs. Carol assisted David with managing his oxygen and medications, while also taking care of various tasks around the home that David was typically responsible for.



Carol became exhausted while continuing to work full-time and simultaneously being a full-time caregiver to her husband. Carol desperately realized she needed support.

Carol reached out to their two adult children to vent about her frustrations and struggles revolving around her role as a caregiver. Her children were available to provide moral support, encouragement, and suggestions to Carol. However, they were not available to be physically present to help with the veteran's daily care needs.

Both of their adult children reside in another state, work full-time jobs, and have families of their own, so they recommended that she consider getting a home health aide. Carol immediately rejected this idea because she knew David would not be comfortable having a stranger in their home.

A few weeks later, during a routine appointment with David's primary care doctor at the VA, the doctor checked in with Carol and asked how she was doing. Carol expressed feeling overwhelmed with the veteran's care needs, and the doctor encouraged her to speak with the PACT social worker for additional support.

Carol expressed her concerns to the PACT social worker who acknowledged how common it is for caregivers to experience burnout and validated the challenges she was experiencing. The PACT social worker provided information about in-home care services, respite care, and the Caregiver Support Programs. The social worker also encouraged her to reach out to the National VA Caregiver Support Line for additional resources and emotional support.

Carol was thankful for the support and resources provided to her, but she was still hesitant. Carol was not used to asking for or accepting help and she has always been self-reliant. Carol was very prideful and decided to continue pushing forward in supporting her husband the best way she knew how. Over the next few weeks, Carol continued to work but she came up with a routine to make sure all of David's care needs were being met while she was away.

Carol would wake up one hour earlier than usual to make sure David had his medicine, breakfast, shower, and dressed for the day. Before leaving for work, Carol made sure David was sitting comfortably in his recliner and had access to what he needed until she returned home during her lunch break. She also would call him periodically throughout the day to check on him and ensure he was okay. Her routine seemed to be going smoothly until David had a fall while she was at work and had to go to the hospital. Carol decided now was the time to reach out for more support.



Carol was at a crossroads and although she loved her job, she knew that she could no longer work full-time while simultaneously providing the care and support her husband needed and deserved. Carol took the PACT social worker's advice and reached out to the VA.

Carol called the Caregiver Support Line (CSL) and spoke with a CSL Responder who was attentive to her needs. Carol felt relieved having been allowed an opportunity to express her challenges and feelings around caregiving for a disabled Veteran. She was able to process her experiences as a caregiver without feeling judged and was provided emotional support, and information about the Caregiver Support Program.

The CSL responder provided psychoeducation and talked with Carol about coping strategies that she could incorporate into her daily schedule that could help prevent burnout. The responder asked Carol to consider engaging in activities that bring her joy and help her pause, relax and rejuvenate.

Carol reported her self-care activities consisted of getting up before her husband to enjoy a cup of coffee on her deck, reading a book during her breaks at work, and doing yoga once a week. Carol stated she wished she had more time to engage in self-care but disclosed that it is difficult to do so while working full-time and she cannot afford to leave her job.

The CSL responder empathized with Carol's situation and provided more information about the VA Caregiver Support Programs. Carol was informed of the benefits and resources from Program of General Caregiver Support Services (PGCSS) and Program of Comprehensive Assistance for Family Caregivers (PCAFC). Carol decided to proceed with applying for PCAFC due to the financial benefit that is included with this program and if approved, it would allow her to resign from her job.

Carol continued her consistent routine of working and providing care to her husband for the next few months while her application was being reviewed. Carol was happy to learn that she had been approved for the program and as a PCAFC primary caregiver, Carol now had access to many resources such as mental health counseling, respite care, medical insurance, and peer support. The stipend payment also allowed Carol to resign from her job and still maintain their monthly expenses.

Carol remained active in PCAFC for the next two years and utilized the various resources included with this program. The respite care allowed her to visit her children and grandchildren when her husband was too sick to travel. Carol was also able to access mental health resources to help her process the challenges of being a caregiver of a veteran with complex medical needs.



Carol was ecstatic to have more time to practice self-care such as attending her own medical appointments, going to the salon to get her hair done, and partake in one of her favorite past times which is baking for her friends and neighbors.

During this time, David's health continued to deteriorate, and Carol continued to provide the care and support he needed. However, after two years of battling congestive heart failure and cancer, David eventually succumbed to his illnesses and sadly passed away. Carol was understandably devastated and heartbroken over the loss of her husband and she struggled to manage all her different emotions.

Let's pause here for just a moment and talk about what those emotions are.

You can never fully prepare for your loved one's passing. Even when you know their health has declined and their passing seems imminent, you will never be ready. The grief process is different for everyone. For some, they may be having difficulty transitioning through the different stages of grief and may be stuck dealing with a negative emotion. For others, they may be able to progress through all or most of the various stages of the grief process and are able to cope in a healthy manner.

The stages of grief are Denial, Anger, Bargaining, Depression, and Acceptance. Elisabeth Kübler-Ross was a Swiss-American psychiatrist, and a pioneer in near-death studies. She was also the author of the internationally best-selling book, "On Death and Dying" where she first discussed her theory of the five stages of grief, also known as the "Kübler-Ross model". The grieving process is not linear, and it is normal to experience these emotions singularly or simultaneously, and in no specific order.

Denial refers to the period of grieving during which a person refuses to accept the reality of a situation. Denial is different than not understanding. It is a defense mechanism that helps us protect ourselves from the shock of the upsetting hardship. A period of denial can be normal and even helpful during the grieving process, as we work to process a difficult situation.

Examples of denial include refusing to accept or acknowledge the death; refusing or avoiding the topic in conversation; and stating the loss is not true, or that the source of the news is unreliable.

The next stage is anger. Once a person comes to understand the information they received, and accepts the reality of a death, they often experience anger. Anger can be a natural response directed toward oneself, family members, doctors, your Higher Power, or even the deceased. Anger is a normal part of the grieving process,



though it may seem hurtful or offensive to loved ones. Often, anger is just a manifestation of grief, and can present itself in various ways.

Examples of anger include blaming a medical doctor for not preventing an illness; blaming family members for a lack of care or support; feeling anger toward God or a higher spiritual power; feeling angry with oneself or blaming oneself for the death; experiencing a short temper or loss of patience.

When we experience grief, we often feel hopeless and overwhelmed. It is common to be overcome by statements of "what if" and "if only," as we experience a loss of control over what is happening. During the bargaining stage of grief, a person attempts to negotiate or make compromises. We try to make agreements with ourselves, or a deal with a higher power, in exchange for feeling less sad or having a different outcome. Bargaining is often irrational.

Examples of bargaining phrases include: "If only I had brought her to the doctor sooner, this would have been cured" or "If only I had been around more, I would have noticed something was wrong" or "God, if you bring him back, I promise I will never lie again".

Depression is a feeling of sadness and hopelessness that often results with the loss of a loved one. While the earlier stages of grief help to protect us from the emotional pain experienced with loss, often these feelings are inevitable.

Symptoms of depression include feelings of sadness, loss of interest in activities you normally enjoy, changes in sleep, significant changes in weight, lack of energy, feeling agitated or restless, feeling worthless or guilty, decreased concentration.

Feelings of depression are a natural reaction to grief. Following the loss of a loved one, acute grief can impact your functioning for a limited time. Bereavement can lead to Prolonged Grief Disorder if these feelings persist and continue to cause significant impairment and distress in your life for more than one year. Prolonged grief disorder is a diagnosable medical condition and can become disabling if not managed appropriately.

The final stage of the Kubler-Ross's model is acceptance. In this last stage, acceptance refers to the period of grief when we finally come to terms with accepting the reality of our loss. When we have reached this stage of acceptance, we no longer deny or struggle against our grief. During this time, we work to focus our energy on celebrating the life of our loved one, cherish the memories that were shared, and make plans for moving forward.



Now that we learned about the five stages of grief, we will turn our attention back to Carol for a moment and discuss how she is navigating the grieving the process. Carol was fortunate to have family and friends nearby to provide support and comfort however, she was not sure who to notify and what support would be available to her through the VA now that her husband has passed away.

After the funeral services Carol reached out to her local Caregiver Support Coordinator (CSC) to report her husband's passing. The CSC offered condolences and ensured Carol she would receive one lump sum stipend payment (equal to 90 days) to help transition out of the program. The CSC also recommended that she notify the Veterans Primary Aligned Care Team or PACT, and that she continue to reach out to their office or the CSL for emotional support.

Carol took their advice and reached out to the CSL for additional support and resources. The CSL social worker immediately offered condolences regarding the passing of the Veteran and asked Carol how she has been coping with her loss. Carol expressed that she misses her husband terribly, but she is trying to find the strength to get the Veteran's affairs in order. The CSL social worker held space during the call to allow Carol time to process her thoughts and feelings revolving around her grief and provided guidance around the next steps.

Funeral arrangements may feel overwhelming and chaotic. This may be the most challenging step. We are comfortable talking about major life events such as births, weddings, school graduations, etc., but many do not want to talk about death, even though it is inevitable. After our loved-one passes, and especially if their passing was sudden and unexpected, it can be emotionally taxing to juggle these responsibilities while actively grieving.

The National Cemetery (NCA) and the funeral director are both excellent point of contacts to help make the final arrangements for your Veteran. The NCA can provide burial and benefit information, and the funeral director can help with the coordination of the burial and military honors.

Carol was also advised to notify the Veterans Benefits Administration (VBA) since she mentioned the Veteran was receiving VA disability compensation. It was explained to Carol that notifying the VBA as soon as possible can help avoid any over-payment. The VBA is also an excellent resource for benefit information for the surviving spouse (i.e. Dependency and Indemnity Compensation (DIC), Aid & Attendance, Survivor's pension).



Carol was also encouraged to notify other governmental programs such as Social Security Administration, as soon as possible and inquire about eligibility for any survivor benefits through their program.

During the conversation, Carol asked a rhetorical question about what other VA services and supports may be available to her if the time comes when she needs home care services or long-term care and/or assisted living. The CSL social worker gently informed Carol the VA does not have a program that provides direct services or hands on care such as in home services to the surviving spouse of a Veteran. However, the support that most surviving spouses receive is monetary where they can use their benefits to pay for medical services they may need. The CSL social worker wished Carol well and encouraged her to contact the CSL as needed for emotional support, bereavement resources, and general questions.