



Introduction and Table of Contents



WHVP **Wisconsin Hospice/ Veteran Partnership**

Improving End of Life Care for Rural and Homeless Veterans

This toolkit and the enclosed DVDs and CD is provided as training materials for staff who come into contact with members of the community who may be Veterans. Please use these materials with your staff and for presentations to facilities that work with your agency who may also be serving Veterans and their families.

The toolkit contains:

Hospice and Palliative Care Experts of Wisconsin (HOPE) web site where many of the materials contained in this toolkit and others resources are available

<http://hopeofwisconsin.org/ProgramsToolkits.aspx> (click on Veteran Partnership)

Military Health History Pocket Card information

CD of the files of materials contained in this toolkit

DVD of a narrated powerpoint presentation on the Unique Needs of Veterans at End of Life

Audio only CD of the powerpoint presentation for staff training during “Drive Time”

PTSD information

Family Caregiver Education Materials on PTSD

Wounded Warrior: Their Last Battle - Facilitator Guide and DVD by Deborah Grassman

Process of Enrollment of Hospice Veterans for VA Care: Catastrophically Disabled Evaluation

Brochure on Veterans Services and Wisconsin State and Federal Veteran Resource contact information

Thank you pins for Veterans from the Wisconsin Hospice Veteran Partnership

Competency and Self Assessment for Employee Performance and Learning

Peace At Last a book by Deborah Grassman

A press release is included with more details about the grant and web sites that you may find helpful as a resource for end of life care and caring for Veterans and their families.

www.wehonorveterans.org

Evaluation form to give feedback on the contents of this toolkit.

Please call Teri Rostberg at Hope Hospice and Palliative Care to obtain a copy of the toolkit materials at 715-748-3434 or 1-877-375-0919. Thank you for your interest to better serve Veterans and their families.

WHVP

Wisconsin Hospice/
Veteran Partnership

Improving End of
Life Care for Rural
and Homeless
Veterans

First Responders, emergency rooms and community agencies are often the first to be involved with rural and homeless Veterans and their families when their care may be transitioning from acute to more chronic and serious illness. We are offering resources for agencies and families as they seek out information and community services to fill unmet needs. Hospice organizations around the state will have access to these resources as well and are available on the HOPE of Wisconsin web site.

In recognition of a need to increase awareness of the unique needs of Veterans in the last year or so of life, a Rural and Homeless Veterans Outreach Grant was awarded to Hope Hospice and Palliative Care in Medford Wisconsin along with the Veteran Administration facilities in Tomah and Madison. This grant makes available resources, education and training materials to a wide audience of providers, agencies and veterans and their families as well as the general public.

We would like to offer resource materials and/or a Toolkit to your organization. I have enclosed a list of materials we have available. The resource materials available in the Rural and Homeless Veteran Toolkit are made available free of charge from this grant and include:

DVD and Audio CD available for training and copies of resources
Military History Pocket Card
PTSD information
Peace At Last a book by Deborah Grassman
Wounded Warrior a DVD by Deborah Grassman
Thank you pins for Veterans from the Wisconsin Hospice Veteran Partnership
Brochure on Veterans Services and Veteran Resource contact information

Information related to some of these toolkit materials is also available on the following web sites:

<http://hopeofwisconsin.org/ProgramsToolkits.aspx> (click on Veteran Partnership)
www.wehonorveterans.org

A press release is included with more details about the grant and web sites that you may find helpful as a resource for end of life care and caring for Veterans and their families.

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Reaching Out: Quality Hospice & Palliative Care for Rural & Homeless



Veterans Toolkit

Materials developed by members of the Hospice Veteran Partnership of Wisconsin and Northern Michigan: Teri Rostberg, BS, MHA, Executive Director of Hope Hospice in Medford WI, Jolene Renda, DNP, APN/CNP VISN 12 Palliative Care Coordinator for the Tomah VA Medical Center and Sheila Schroedl, LCSW Palliative Care Coordinator at the William S. Middleton Memorial Veterans Hospital in Madison pulled together this toolkit as current members of the WI HVP steering committee. These materials are available on the HOPE of Wisconsin web site. <http://hopeofwisconsin.org/ProgramsToolkits.aspx>

The HVP of Wisconsin and Northern Michigan Steering Committee is comprised of about 15 members representing the following groups of stakeholders:

1. State Hospice Organization
2. Community hospice agencies
3. VA facilities - VISN, VA Medical Centers, Community-Based Outpatient Clinics (CBOC)
4. State Veterans Homes ([click here](#))
5. County Veterans Service Organizations (CVSO)
6. Veteran and family member
7. Other community, state and national organizations interested in improving care through the end-of-life for veterans

The HVP of Wisconsin and Northern Michigan Steering Committee convenes primarily by conference calls quarterly or face-to-face meetings of the general membership. Members are expected to contribute their time, expertise, and energies as appropriate in meeting the purpose of the coalition, including, but not limited to:

- Representing the interests of their stakeholders group
- Participating in the regular meetings
- Building partnerships
- Seeking funding to support HVP activities
- Conducting state-wide and regional educational events
- Making recommendations regarding improving hospice and palliative care services for veterans in Wisconsin and Northern Michigan

Training Opportunities

Deb Grassman "Combat Veterans and PTSD" ([Click here](#))

Deb Grassman "Veterans Under Served" ([Click here](#))

HEN ELNEC for Veteran's Training ([Click here](#))

Education on Hospice, Grief, Veterans, Rural, Caregiving and LGBT ([click here](#))

EPEC (Education in Palliative and End of Life Care) for Veterans ([click here](#))

NHPCO We Honor Veterans ([click here](#))

These materials made available through a grant application made through NHPCO and the VA.

Web address is <https://hopeofwisconsin.org/ProgramsToolkits.aspx> then click on Veterans Partnership

PDF Downloads:

- [Military Emblems](#)
- [Military Service History Pocket Card](#)
- [Patriotic Quotes and Verses](#)
- [Patriotic Recognition Opportunities](#)
- [The Unique Needs of Veterans at the End of Life](#)
- [VA Recognition Opportunities](#)
- [VA Facilities Map](#)
- [Veterans Appreciation Certificates](#)
- [Veterans Benefits Fact Sheets](#)
- [Veterans Brochure](#)
- [Veterans Competency Summary](#)
- [Veterans Competency Worksheet](#)

The Military Health History Pocket Card is a pocket-sized resource to provide **all VA and community health professions trainees** a guide to understanding health issues that are unique to veterans.

VA's students and trainees generally are **young** while **our veteran patients are older** and have had experiences in a different time and place. This card helps to **bridge that gap**.

The card suggests questions that invite the veteran to tell his/her own story while the web site provides information that will offer **greater insight** into the veteran's story.

It is important to make the patient aware that his/her unique experiences as a veteran are of concern to clinicians.

Who should receive the Military Health History Pocket Card?

All health professionals

How is the Military Health History website used?

It provides background information related to the questions on the Pocket Card. Summaries of veterans' health issues as well as links to other web sites are provided.

The Card can be used to capitalize on many learning opportunities:

- Give trainees better understanding of the veteran's perspective.
- Encourage trainees and staff to take more careful, veteran-centered histories.
- Stimulate case discussions augmented by information found on the web site.
- Consider discussing issues presented on the card during daily work rounds or informal case-based conferences.

<p>Department of Veterans Affairs</p> <p>Answers to these questions will provide information helpful in understanding patients' medical problems and complaints, and in establishing rapport and therapeutic partnerships with military service members and Veterans. Answers may also provide a basis for timely referral to specialized medical resources.</p> <p>Additional Resources</p> <p>Office of Academic Affiliations www.va.gov/oa/pocketcard</p> <p>Veterans Health Initiative Independent Study Courses www.publichealth.va.gov/vethealthinitiative</p> <p>War-Related Illness and Injury Study Center www.warrelatedillness.va.gov</p> <p>Office of Public Health and Environmental Hazards www.publichealth.va.gov</p> <p>Information for Veterans: Eligibility for Compensation and Pension Benefits www.vba.va.gov/hv21</p>	<p>Military Health History POCKET CARD FOR CLINICIANS</p> <p>Tell me about your military experience.</p> <ul style="list-style-type: none"> • When and where do you (did you) serve? • What do you (did you) do while in the service? • How has military service affected you? <p>If your patient answers "Yes" to any of the following questions, ask: "Can you tell me more about that?"</p> <ul style="list-style-type: none"> • Did you see combat, enemy fire, or casualties? • Were you or a buddy wounded, injured, or hospitalized? • Did you ever become ill while you were in the service? • Were you a prisoner of war? <p>Tell your patient about VA's MyHealthVet</p> <p>Trusted health info Personal Health Journal Online Rx refill VA benefits & resources Federal resources Manage your health</p> <p>www.myhealth.va.gov</p> <p>provided by: Office of Academic Affiliations VETERANS HEALTH ADMINISTRATION April 2011</p>	<p>Unique Health Risks</p> <p>Operation Enduring Freedom, Operation Iraqi Freedom, Operation New Dawn, (OIF/OND)</p> <p>Combined Penetrating, Blast Trauma, and Burn Injuries (Blast Injuries)</p> <p>Dermatologic Issues Embedded Fragments (shrapnel) Leishmaniasis Mental Health Issues Multi-Drug Resistant Acinetobacter Reproductive Health Issues Traumatic Amputation Traumatic Brain or Spinal Cord Injury Vision Loss</p> <p>Gulf Wars</p> <p>Chemical or Biological Agents Depleted Uranium (DU) Dermatologic Issues Exposures to Smoke Immunizations Infectious Diseases (e.g., Leishmaniasis) Reproductive Health Issues</p> <p>Vietnam</p> <p>Agent Orange Exposure Hepatitis C</p> <p>Cold War</p> <p>Nuclear Weapons Testing (atomic veterans)</p> <p>WWII/Korea</p> <p>Agent Orange Exposure Cold Injury Chemical Warfare Agent Exposures Exposure to Nuclear Weapons (Including Testing or Cleanup)</p>	<p>Issues of Concern</p> <p>Military service members and all Veterans should be asked the following questions:</p> <p>General</p> <ul style="list-style-type: none"> • Do you have a claim pending for illness or injury related to your military service? • Do you have a service-connected condition? • Do you know how to initiate a claim if you think you might be entitled? (answer: Call VHA at 1-800-827-1000) • Did you participate in any experimental projects? • Were you exposed to noise, chemicals, gases, demolition of munitions, pesticides, or special paints? <p>Sexual Harassment, Assault, and Trauma</p> <ul style="list-style-type: none"> • Have you ever experienced physical, emotional, or sexual harassment or trauma? • Is this past experience causing you problems now? • Do you want a referral? <p>Hepatitis C Virus (HCV) Infection</p> <ul style="list-style-type: none"> • Have you ever had a blood transfusion? • Have you ever injected drugs such as heroin or cocaine? <p>Living Situation</p> <ul style="list-style-type: none"> • Where do you live? • Is your housing safe? • Are you in any danger of losing your housing? • Do you need assistance in caring for dependents? <p>Stress Reactions/Adjustment Problems</p> <p>In your life, have you ever had an experience as horrific, frightening, or upsetting that, in the past month you...</p> <ul style="list-style-type: none"> • Have had nightmares about it or thought about it when you did not want to? • Tried hard not to think about it or went out of your way to avoid situations that reminded you of it? • Were constantly on guard, watchful, or easily startled? • Felt numb or detached from others, activities, or your surroundings?
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Veterans: An Underserved Population

By Deborah Grassman, ARNP

January 2007

In 2006, 600,000 veterans died, comprising about 25% of all Americans who died that year. Most of the veterans did not die in a Veterans' Affairs Medical Center (VAMC), but rather in other facilities or at home. Yet health care providers outside the VA system generally are not familiar with the unique needs of the veteran population.

Recent legal changes have been made to respond to the needs of these dying veterans. VA facilities now must either provide hospice and palliative care services or purchase services from community hospices for all enrolled veterans. To facilitate this process, Hospice-Veterans Partnerships (HVPs) have been established in nearly every state.

Veterans have unique, often unrecognized hospice needs that complicate the dying process. For example, military culture instills stoic values that might interfere with peaceful dying. A “fight to the bitter end” attitude complicates death, requiring skillful intervention from hospice clinicians. On a battlefield, death is the enemy and “surrender” is failure; yet much of hospice work focuses on “letting go” and “surrendering.” Additionally, combat veterans’ last experience with death may have been filled with fear, horror, and helplessness on the battlefield. These associations may also interfere with a peaceful death. On the other hand, because death is no stranger to combat veterans, they often report that they’ve faced death before and are *not* afraid of it. To address these barriers, here are some suggestions for improving hospice care provided to dying veterans.

- Assess if patients are combat veterans or have experienced any other military trauma. (Don’t assume all combat veterans sustained trauma; some had “safe” assignments. Don’t assume all non-combat veterans did NOT sustain trauma; many served in dangerous assignments.)
- Anticipate that veterans may underreport pain or fear because of deeply-held stoic values.
- Remember that combat veterans may have sustained mental, emotional, social, spiritual, and moral injuries. Moral injuries especially might complicate death. Those who have not only witnessed trauma but *caused* it may need encouragement to touch the moral injury and engage in the work of forgiveness. Don’t dismiss their guilt with platitudes; instead, create a safe emotional environment for guilt to emerge.
- For patients with Post-Traumatic Stress Disorder (PTSD), eliminate as many “triggers” as possible. Remember that coming into a hospital (especially a VA hospital) often triggers past military memories of barracks, procedures, unsafe environments, past combat hospitalizations, visiting injured comrades, etc. A government hospital and its employees may not be trusted by Vietnam vets. On the other hand, a VA hospital can be like

"coming home", supporting their soldier identity while providing camaraderie and a sense of belonging.

- Loud or unexpected sounds will startle people with PTSD. Don't touch them without first letting them see you or calling out their name.
- Be aware that confinements (tight bed linens, etc.) may cause agitation for veterans who were former Prisoners of War (POWs).
- Distinguish between "terminal restlessness" and PTSD. Terminal restlessness is often treated with **anti-anxiety drugs**, but these drugs may have a paradoxical reaction with veterans experiencing agitation from PTSD. **Phenergan and Haldol may** work better.
- Remember that some of the usual treatments for PTSD may not be practical in the last few days of life because the conscious mind is weakening. For some, grounding in reality is not feasible; instead, enter the metaphor or hallucination with them and provide whatever they need in order to feel safe. For example, if they report that Vietcong are under their bed, put the mattress on the floor. Safety is always the essential ingredient.
- Express appreciation to all veterans for their service to our country. Provide symbols of appreciation for that service: certificates, pins, cards, handshakes.
- Acknowledge to the family the hardship the military experience might have had on *their* lives. Provide symbols to them for their sacrifices made to support the veteran.
- Remember that stoic veterans might not attend bereavement groups to attend to their own grief needs. They might view support groups as forums for "cry babies;" alternative modalities for providing bereavement care often need to be provided. Also remember that "routine" bereavement care for combat veterans may uncover much unresolved grief from deaths of comrades on the battlefield.
- Many people with PTSD surround the trauma imprint with a wall of silence. Offering some quotes by other veterans may help them give voice to their stories. Here are some examples:
 - "Sometimes, a vet will tell me he lost his soul in ____ (WWII, Korea, Vietnam). Did something like that happen with you?"
 - "Sometimes combat veterans tell me that when they killed others, they killed a part of themselves. Did you experience anything like that? Is there anything about your military experience that might still be troubling you?"
- Validating suffering can also be important:
 - "I would think the world was pretty confusing after you returned from war. All the rules had changed; much of what you were taught was violated..."
 - "I would guess there have been times when you've been pretty angry at God for allowing the world to have war in it...for not intervening to protect people from cruelty..."

- o “Sometimes veterans tell me feeling helpless makes them angry. I imagine it’s hard for a soldier to learn how to surrender...to let go...”
- Penetrating stoic walls can also be important:
 - o “I know it can be hard for men to express their feelings. But now is not a time to pretend like nothing is going on....that nothing has changed.”
 - o “There’s no shame in feeling your feelings. The shame is in not sharing them with those who love you. The shame is in not asking for help when you need it. The shame is in not recognizing your needs when you have them.”
 - o “Many veterans tell me they feel_____ (angry, scared, sad, guilty) when something like this happens.”
- Provide information about veteran burial benefits and the location of the closest national cemetery. (www.cem.va.gov)
- Consider transporting patients to the funeral home under an American flag quilt.
- Assign volunteers who are veterans to patients who are veterans.
- If you have an inpatient hospice facility, consider decorating one wing with military décor or symbols for veteran patients.
- Feature articles about veterans or veteran volunteers in newsletters.
- Participate in the NHPCO and National VA Hospice Veteran partnership in your state. (Contact Diane Jones at djones@ethosconsult.com).
- Support or provide ceremonies of recognition for veterans on Memorial Day, Independence Day, and Veterans Day.

The following websites provide more information:

[www.Va.gov/oaarchive/Va Transforms End of Life Care.pdf](http://www.Va.gov/oaarchive/Va_Transforms_End_of_Life_Care.pdf)
www.eperc.mcw.edu
www.va.gov www.pnpco.com
www.findingourway.net

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Quick Tips for Post Traumatic Stress Disorder (PTSD)

Potential Triggers for PTSD/Anxiety

- ★ Pain
- ★ Decreased functional capacity
- ★ Helplessness
- ★ Fear and Anxiety
- ★ Restraining
- ★ Medication side-effects
- ★ In some people who are accustomed to feeling tense, the sensation of relaxation may paradoxically create discomfort and anxiety

PTSD Assessment

- ★ PTSD diagnosis requires the experience of a traumatic event in addition to symptoms that can be described in three clusters:
 - Re-experiencing symptoms (repetitive disturbing memories, nightmares, and hallucination-like flashbacks)
 - Avoidance symptoms (attempts to avoid reminders of trauma—objects, places, people)
 - Hyperarousal symptoms (hypervigilance, irritability, exaggerated startle response, and insomnia)

Other considerations:

- ★ For veterans experiencing EOL with no prior symptoms of PTSD, this may be due to the unconscious mind, where prior traumas were repressed, taking over the conscious mind as their medical condition progresses.
- ★ Sometimes clinicians may confuse a flashback (re-experiencing a traumatic event as if it is happening at the moment) for agitated delirium. Flashbacks tend to be more short-lived than episodes of delirium. Delirium can be related to PTSD. Agitated delirium can be triggered by a number of causes including medication withdrawal, physical discomfort. Constant reorientation can cause more agitation. Creation of a distraction and a relaxing, calm environment is helpful.
- ★ Anxiety feeling of loss of control and uncertainties can also be related to PTSD. Medications can also cause anxiety or withdrawal from some medications can cause anxiety. Listening, assurance, concrete information and appropriate realistic support can be helpful.
- ★ Anticipate that they might UNDERREPORT physical and emotional pain. (The veteran with subclinical PTSD veteran may underreport pain which contrasts with those veterans diagnosed with PTSD)
- ★ Anticipate that they might UNDERREPORT fear.
- ★ Be aware that **Asian Ancestry** in the healthcare provider may be a trigger for WWII (Pacific theatre), Korean, and Vietnam vets. Don't take this personally. (This does not necessarily have anything to do with racism)

Potential Effect of PTSD

- ★ Difficulty sleeping due to nightmares
- ★ Disturbing thoughts and memories that patient has difficulty avoiding
- ★ Mild paranoia
- ★ Vivid hallucinations
- ★ Intense anxiety (Fight/Flight/Freeze) alternating with "no feelings at all" (emotional numbing).
- ★ Distrust of others
- ★ Veterans may isolate themselves and avoid social situations.
- ★ Threat to life can mimic the original trauma, and exacerbate previously mild symptoms
- ★ The normal process of life review can lead to intense anxiety, sadness, guilt, anger
- ★ Avoidance as a coping mechanism may lead to poor medical adherence or poor communication with medical staff
- ★ Distrust in authority can lead to excessive questioning of providers' actions and refusal of care
- ★ Patients with PTSD may lack caregivers because of a history of social isolation and avoidance

Treatment at PTSD at End of Life

- ★ Drugs to reduce intensity of symptoms (TCA, SSRI, Benzodiazepines, Anticonvulsants, Antipsychotics)
- ★ Psychotherapy (often not possible during brief admissions)
- ★ Psychosocial symptom management (helpful for brief admissions)
- ★ Be aware of possible paradoxical reactions with meds. Be cautious in using sedatives that might cause further mis-cuing and further loss of control, which only makes them fight harder to re-gain control. (use **Haldol**, **compazine**, **phenergan** as alternatives)
- ★ Relaxation training and breathing re-training

Possible Responses

- ★ Signs a Veteran may be having a flashback
 - Behaving as if in warfare
 - Looking extremely fearful
 - Freezing and staring into space
 - Making statements such as “look out” or “I see the enemy”
- ★ Engage in verbal “grounding,” while maintaining physical space for safety
“Mr. _____, we’re in your bedroom, in your home in Milwaukee, and my name is _____”
- ★ Enter metaphor with them. (Battle metaphors are common)
- ★ Listen patiently and warmly, and allow them to stop when they are ready
- ★ Reassurance (providing information to soothe patient’s anxieties)
- ★ Avoid attempts to comfort that actually serve to stifle the topic (“It’s ok,” “Don’t cry,” “That was a long time ago,” etc.)
- ★ Inform them that it is very normal to have these memories and to feel distressed by them, especially near the EOL
- ★ Work with healthcare providers and family about how “to avoid” triggering PTSD symptoms
- ★ “Is there anyone to whom you would like to speak about these concerns? A chaplain? A social worker?”

★ Psychological Management of PTSD

- ★ Consider ways in which one's approach with the patient may trigger fear, startle, avoidance, or other reactions, and work toward altering one's approach
- ★ Ask patient about behaviors that may trigger PTSD
 - Shouting
 - Pointing
 - Touching
 - Entering room unannounced
 - Ordering them what to do rather than providing options
- ★ Ask patient about behaviors that may help
- ★ Provide a nightlight
- ★ Awaken patients by stating their name rather than touching
- ★ Increase privacy if appropriate.
- ★ Normalize the patient’s experience – some Veterans may not know about PTSD
- ★ Affirm the FEELING aspect of the death experience, especially the tears and fears (which the military culture taught them to disdain).
 - “You probably saw a lot of ugly things in the war. Can you tell me a few that still trouble you?”
 - Develop sensitivity to the sequela of war!
- ★ Thank the veteran for serving your country and giving you your freedom. You may want to consider one of the following:
 - Post a certificate of appreciation.
 - Patriotic calendars.
 - Pin an American flag on them with a personal message.
- ★ For combat veterans - **Listen and provide witness to their stories.**
- ★ Determine their Emotional Pain with a scale: **Emotional Pain Scale** (0=Serenity/10=Turmoil)
- ★ Understand and accept their pain, anger, shame, fear, helplessness – especially when it presents in angry, fearful, despairing, and ugly, non-compliant ways.
- ★ Recognize confusion/agitation for the PTSD that it might be (not terminal restlessness).
- ★ If the veteran is experiencing flashbacks that the enemy soldiers are under the bed, place the mattress on floor .
- ★ Avoid all types of restraints (especially if they have been Prisoners Of War).
- ★ Assess for environmental triggers, realizing that weather, holidays, helicopters, surgery, own death or family or friend’s death may be triggers for PTSD.
- ★ If a Vietnam or Korean veteran speaks about how Americans treated them, apologize. If Vietnam veteran speaks about never being welcomed home, welcome him.
- ★ Educating Family/Friends on the symptoms that they are witnessing (which may be very different than how the veteran behaved in the past), may be due to PTSD and provide them with some suggestions on how to manage the symptoms.

PTSD and Grief

- ★ For veterans who have served in dangerous assignments, their past experiences with death might have been violent and mutilating. They bring this experience with them whenever they encounter death or grief.
- ★ In combat there was no time to mourn the death of comrades; soldiers had to keep moving or they would be killed. With grief on hold, their bereavement needs may stagnate, but facing their own death decades later can trigger PTSD or activate grief from the many past losses during combat, deaths that were often mutilating or guilt-laden.
- ★ If a veteran has PTSD, he/she probably does not trust easily or is reticent to reach out to strangers trying to provide bereavement care. They might cope with grief by isolating or “bunkering down”, which is often counterproductive. Initial approaches may need to be modified and should focus on gaining trust.
- ★ PTSD may create multiple families, estrangements, or forgiveness issues. Any of these can complicate peaceful dying and effective grieving.
- ★ Veterans who are receiving a VA pension that ends with their death, might fight hard to stay alive for financial purposes. Concern about their spouses welfare might cause them to want futile medical treatments. This focus sometimes interferes with anticipatory grieving for their own life, and it prevents essential dialogue with family members which complicates their own bereavement.

Resources:

Seahorn, J. J., & Seahorn, A.H. (2008). *Tears of a Warrior: A Family's Story of Combat and Living with PTSD*. Fort Collins, CO: Team Pursuits.

Feldman D.B., & Periyakoil, V.S. (2006). Posttraumatic stress disorder at the end of life. *Journal of Palliative Medicine*, 9, 213-218.

Grassman, D.L., (2009). *Peace at last: Stories of hope and healing for veterans and families*. Vandemere Press: St. Petersburg, FL

www.WeHonorVeterans.org

PTSD Checklist – Civilian Version (PCL-C)

Patient's Name: _____

Instruction to patient: Below is a list of problems and complaints that veterans sometimes have in response to stressful life experiences. Please read each one carefully, put an "X" in the box to indicate how much you have been bothered by that problem *in the last month*.

No.	Response:	Not at all (1)	A little bit (2)	Moderately (3)	Quite a bit (4)	Extremely (5)
1.	Repeated, disturbing <i>memories, thoughts, or images</i> of a stressful experience from the past?					
2.	Repeated, disturbing <i>dreams</i> of a stressful experience from the past?					
3.	Suddenly <i>acting or feeling</i> as if a stressful experience <i>were happening again</i> (as if you were reliving it)?					
4.	Feeling <i>very upset</i> when <i>something reminded</i> you of a stressful experience from the past?					
5.	Having <i>physical reactions</i> (e.g., heart pounding, trouble breathing, or sweating) when <i>something reminded</i> you of a stressful experience from the past?					
6.	Avoid <i>thinking about</i> or <i>talking about</i> a stressful experience from the past or avoid <i>having feelings</i> related to it?					
7.	Avoid <i>activities</i> or <i>situations</i> because <i>they remind you</i> of a stressful experience from the past?					
8.	Trouble <i>remembering important parts</i> of a stressful experience from the past?					
9.	Loss of <i>interest in things that you used to enjoy</i> ?					
10.	Feeling <i>distant</i> or <i>cut off</i> from other people?					
11.	Feeling <i>emotionally numb</i> or being unable to have loving feelings for those close to you?					
12.	Feeling as if your <i>future</i> will somehow be <i>cut short</i> ?					
13.	Trouble <i>falling</i> or <i>staying asleep</i> ?					
14.	Feeling <i>irritable</i> or having <i>angry outbursts</i> ?					
15.	Having <i>difficulty concentrating</i> ?					

16.	Being "super alert" or watchful on guard?					
17.	Feeling jumpy or easily startled?					

Weathers, F.W., Huska, J.A., Keane, T.M. *PCL-C for DSM-IV*. Boston: National Center for PTSD – Behavioral Science Division, 1991. *This is a Government document in the public domain.*



What is PTSD?

Posttraumatic Stress Disorder (PTSD) is an anxiety disorder that can occur following the experience or witnessing of a traumatic event. A traumatic event is a life-threatening event such as military combat, natural disasters, terrorist incidents, serious accidents, or physical or sexual assault in adult or childhood. Most survivors of trauma return to normal given a little time. However, some people will have stress reactions that do not go away on their own, or may even get worse over time. These individuals may develop PTSD.

People with PTSD experience three different kinds of symptoms. The first set of symptoms involves reliving the trauma in some way such as becoming upset when confronted with a traumatic reminder or thinking about the trauma when you are trying to do something else. The second set of symptoms involves either staying away from places or people that remind you of the trauma, isolating from other people, or feeling numb. The third set of symptoms includes things such as feeling on guard, irritable, or startling easily.

In addition to the symptoms described above, we now know that there are clear biological changes that are associated with PTSD. PTSD is complicated by the fact that people with PTSD often may develop additional disorders such as depression, substance abuse, problems of memory and cognition, and other problems of physical and mental health. These problems may lead to impairment of the person's ability to function in social or family life, including occupational instability, marital problems and family problems.

PTSD can be treated with with psychotherapy ("talk" therapy) and medicines such as antidepressants. Early treatment is important and may help reduce long-term symptoms. Unfortunately, many people do not know that they have PTSD or do not seek treatment. This handout will help you to better understand PTSD and the how it can be treated.

How does PTSD develop?

PTSD develops in response to a traumatic event. About 60% of men and 50% of women experience a traumatic event in their lifetime. Most people who are exposed to a traumatic event will have some of the symptoms of PTSD in the days and weeks after the event. For some people these symptoms are more severe and long lasting. The reasons why some people develop PTSD are still being studied. There are biological, psychological and social factors that affect the development of PTSD.

What are the symptoms of PTSD?

Although PTSD symptoms can begin right after a traumatic event, PTSD is not diagnosed unless the symptoms last for at least one month, and either cause significant distress or interfere with work or home life. In order to be diagnosed with PTSD, a person must have three different types of symptoms: re-experiencing symptoms, avoidance and numbing symptoms, and arousal symptoms.

Re-experiencing Symptoms:

Re-experiencing symptoms are symptoms that involve reliving the traumatic event. There are a number of ways in which people may relive a trauma. They may have upsetting memories of the traumatic event. These memories can come back when they are not expecting them. At other times the memories may be triggered by a traumatic reminder such as when a combat veteran hears a car backfire, a motor vehicle accident victim drives by a car accident or a rape victim sees a news report of a recent sexual assault. These memories can cause both emotional and physical reactions. Sometimes these memories can feel so real it is as if the event is actually happening again. This is called a "flashback." Reliving the event may cause intense feelings of fear, helplessness, and horror similar to the feelings they had when the event took place.

Avoidance and Numbing Symptoms:

Avoidance symptoms are efforts people make to avoid the traumatic event. Individuals with PTSD may try to avoid situations that trigger memories of the traumatic event. They may avoid going near places where the trauma occurred or seeing TV programs or news reports about similar events. They may avoid other sights, sounds, smells, or people that are reminders of the traumatic event. Some people find that they try and distract themselves as one way to avoid thinking about the traumatic event.

Numbing symptoms are another way to avoid the traumatic event. Individuals with PTSD may find it difficult to be in touch with their feelings or express emotions toward other people. For example, they may feel emotionally "numb" and may isolate from others. They may be less interested in activities you once enjoyed. Some people forget, or are unable to talk about, important parts of the event. Some think that they will have a shortened life span or will not reach personal goals such as having a career or family.

Arousal Symptoms:

People with PTSD may feel constantly alert after the traumatic event. This is known as increased emotional arousal, and it can cause difficulty sleeping, outbursts of anger or irritability, and difficulty concentrating. They may find that they are constantly "on guard" and on the lookout for signs of danger. They may also find that they get startled.

How common is PTSD?

PTSD is common. In the entire population, an estimated 6.8% of Americans will experience PTSD at some point in their lives. Women (9.7%) are more than two and a half times as likely as men (3.6%) to develop PTSD. About 3.6% of U.S. adults (5.2 million people) have PTSD during the course of a given year. This is only a small portion of those who have experienced at least one traumatic event. In people who have experienced a traumatic event, about 8% of men and 20% of women develop PTSD after a trauma and roughly 30% of these individuals develop a chronic form that continues on throughout their lifetime. The traumatic events most often associated with PTSD for men are rape, combat exposure, childhood neglect, and childhood physical abuse. The most traumatic events for women are rape, sexual molestation, physical attack, being threatened with a weapon, and childhood physical abuse.

PTSD is more common in "at-risk" groups such as those serving in combat. About 30% of the men and women who served in Vietnam experience PTSD. An additional 20% to 25% have had partial PTSD at some point in their lives. More than half of all male Vietnam veterans and almost half of all female Vietnam veterans have experienced "clinically serious stress reaction symptoms." PTSD has also been detected among veterans of other wars. Estimates of PTSD from the Gulf War are as high as 10%. Estimates from the war in Afghanistan are between 6 and 11%. Current estimates of PTSD in military personnel who served in Iraq range from 12% to 20%.

Who is most likely to develop PTSD?

Most people who experience a traumatic event will not develop PTSD. However, the risk for developing PTSD increases if people:

- were directly exposed to the traumatic event as a victim or a witness
- were seriously injured during the trauma
- experienced a trauma that was long lasting or very severe
- saw themselves or a family member as being in imminent danger
- had a severe negative reaction during the event, such as feeling detached from ones surroundings or having a panic attack
- felt helpless during the trauma and were unable to help themselves or a loved one.

Individuals are also more likely to develop PTSD if they:

- have experienced an earlier life threatening event or trauma
- have a current mental health issue
- have less education
- are younger
- are a woman
- lack social support
- have recent, stressful life changes

Some research shows that ethnic minorities, such as Blacks and Hispanics, are more likely than Whites to develop PTSD. One reason for these differences is that minorities may have more contact with traumatic events. For example, in Vietnam, Whites were in less combat than Blacks, Hispanics, and American Indians. Researchers are trying to understand other reasons for the differences in PTSD between the ethnic groups. A person's culture or ethnic group can affect how that person reacts to a problem like PTSD. For example, some people may be more willing than others to talk about their problems or to seek help.

How long does PTSD last?

The course of PTSD is variable. This means it can be different for different people and that it can change over time. PTSD usually begins right after the traumatic event but it can also be delayed for many years. For most people symptoms improve over the first year. Treatment also reduces symptoms but for some symptoms can last a lifetime. Roughly 30% of individuals develop a chronic form.

PTSD usually involves periods of symptom increase followed by remission or decrease, although some individuals may experience symptoms that are long lasting and severe. Some older veterans, who report

a lifetime of only mild symptoms, experience significant increases in symptoms following retirement, severe medical illness in themselves or their spouses, or reminders of their military service, such as reunions and anniversaries.

What other problems do people with PTSD experience?

It is very common for other conditions to occur along with PTSD, such as depression, anxiety, or substance abuse. More than half of men with PTSD also have problems with alcohol. The next most common co-occurring problems in men are depression, followed by conduct disorder, and then problems with drugs. In women, the most common co-occurring problem is depression. Just under half of women with PTSD also experience depression. The next most common cooccurring problems in women are specific fears, social anxiety, and then problems with alcohol.

People with PTSD often have problems functioning. In general, people with PTSD have more unemployment, divorce or separation, spouse abuse and chance of being fired than people without PTSD. Vietnam veterans with PTSD were found to have many problems with family and other interpersonal relationships, problems with employment, and increased incidents of violence.

People with PTSD also may experience a wide variety of physical symptoms. This is a common occurrence in people who have depression and other anxiety disorders. Some evidence suggests that PTSD may be associated with increased likelihood of developing medical disorders. Research is ongoing, and it is too soon to draw firm conclusions about which disorders are associated with PTSD.

PTSD is associated with a number of distinctive neurobiological and physiological changes. PTSD may be associated with stable neurobiological alterations in both the central and autonomic nervous systems, such as altered brainwave activity, decreased volume of the hippocampus, and abnormal activation of the amygdala. Both the hippocampus and the amygdala are involved in the processing and integration of memory. The amygdala has also been found to be involved in coordinating the body's fear response.

What treatments are available?

PTSD is treated by a variety of forms of psychotherapy (talk therapy) and pharmacotherapy (medication). There is no single best treatment, but some treatments appear to be quite promising, especially cognitive-behavioral therapy (CBT). CBT includes a number of diverse but related techniques such as cognitive restructuring, exposure therapy, and eye movement desensitization and reprocessing (EMDR). See the National Center for PTSD's website for more information about treatment types and providers.

I think I have PTSD. What can I do now?

Many people who might need help for something like PTSD are afraid to go for help. One out of five people say they might not get help because of what other people might think. One out of three people say they would not want anyone else to know they were therapy. But almost 50% of people say that there is less shame in seeking help now than there has been in the past.

A study that's been done of soldiers coming home from Iraq found that only 40% of service members with mental problems said they would get help. In many cases this was due to the soldiers' fears about what others would think, and how it could hurt their military careers.

If you think you have PTSD there are a number of things you can do. You may want to be evaluated for PTSD by psychiatrist, psychologist, or clinical social worker specifically trained to assess psychological problems. You could also discuss your symptoms with your doctor. Talk to your doctor about the treatments discussed in this handout.

If you do not want to be evaluated but feel you have symptoms of PTSD you may choose "watchful waiting." Watchful waiting means taking a wait-and-see approach. If you get better on your own, you

won't need treatment. If your symptoms do not improve after 3 months and they are either causing you distress or are getting in the way of your work or home life, talk with a health professional.

In a few cases, your symptoms may be so severe that you need immediate help. Call 911 or other emergency services immediately if you think that you cannot keep from hurting yourself or someone else.

What Do I Need to Know?



Some Facts

What is Post Traumatic Stress Disorder?

Post Traumatic Stress Disorder (PTSD) is an anxiety disorder. The diagnosis of PTSD is made when a Veteran has been exposed to a traumatic event in which **both** of the following have occurred: 1) The Veteran experienced or witnessed an event that involved actual or threatened death or serious injury 2) The Veteran experienced a threat to the physical well-being of him/herself or others, and the Veteran's response involved intense fear, helplessness or horror.

Treatment may include: individual therapy and/or group therapy, medication.

Physical and Mental Changes to Expect

While the general symptoms for PTSD are similar, the types and severity of symptoms will differ for each Veteran.

Physical changes may include: difficulty staying or falling asleep; irritability or outbursts of anger; physical reactions — such as profuse sweating, increased heart rate and rapid breathing — when exposed to internal or external cues or reminders of the traumatic event; intense distress when exposed to internal or external reminders of the event such as certain sounds or smells; avoiding any activities, places or people that remind the Veteran of the trauma.

Mental changes may include: recurring and intrusive thoughts about the event; recurring and distressing dreams of the event; acting or feeling as if the traumatic event were recurring — also known as having flashbacks; being unable to recall an important aspect of the trauma; difficulty concentrating; and efforts to avoid thoughts, feeling or conversations associated with the trauma.

Emotional changes may include: intense distress when exposed to internal or external reminders of the event such as certain sounds or smells; a noticeable lack of interest or participation in important activities; feelings of detachment or estrangement from others; limited ability or inability to show affection or love; feelings of a bleak future, such as limited career or family opportunities, and shortened life span; overly alert or on guard — also known as "hyper-vigilance" — and/or exaggerated response when startled.

What Does This Mean for Me?

One of the areas in which you may notice a difference is in your social lives. The Veteran you care for may become uncomfortable in large crowds or unfamiliar places, and so you may find yourself feeling more socially isolated, losing support networks, or feeling the need to compensate for the Veteran you care for in social situations that are uncomfortable for him or her while providing support and encouragement at the same time. You may also have to learn coping skills to manage the stigma that is sometimes associated with mental health disorders.

You may also notice a difference in your personal relationship with the Veteran you care for. It is important to understand that it may be harder to talk to the Veteran due to changes in his or her behavior and/or communication style.

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In addition, if the Veteran is experiencing difficulty managing his or her anger, you may feel like you live in an atmosphere of constant chaos. If the Veteran you are caring for is your spouse or partner, you may experience additional changes in your relationship. This might include feeling worried that your Veteran is no longer emotionally or physically attracted to you due to emotional unavailability, or a decreased interest in physical intimacy and sexual activity. In addition, due to sleep disturbance (for example, insomnia, waking-up frequently, nightmares), many couples choose to sleep in separate beds (and rooms), which may cause further feelings of emotional separation.

At times, you may experience your own feelings of sadness, anger, frustration, discouragement and loss when the Veteran you care for experiences symptoms of PTSD. These reactions are normal, but can be challenging to deal with on your own. Consider seeking help either by confiding in a friend, participating in a support group or consulting a professional mental health practitioner.

Caregiving Tips

1. Learn as much as you can about PTSD by reading, going to lectures, talking with others in similar situations, and talking with the Veteran's treatment team.
2. Consider encouraging the Veteran you care for to seek mental health treatment. VA has proven treatments for PTSD that help Veterans manage their symptoms in all types of environments. Just remember that not everyone is ready to admit they need help, so if there is no threat of harming themselves or others, respect a Veteran's decision about seeking treatment.
3. If the Veteran you care for decides to seek treatment, encourage and fully support that decision. It's important for both of you.
4. Request to be part of the Veteran's treatment. If the Veteran you care for agrees, talk with the mental health providers regularly. Ask questions and take notes.
5. Recognize the Veteran's social and/or emotional withdrawal is due to his or her own issues and not **your** relationship. A Veteran with PTSD will have good days and bad days. Foster relationships with family, friends, and others to stay connected and get support.
6. Learn coping skills to manage stigma sometimes associated with mental health disorders.
7. Pay attention to warning signs of a potential relapse, including an increase in symptoms or other changes in behavior. Keep the psychiatrist and/or therapist, local crisis team, Veterans Crisis Line, and other emergency phone numbers handy.
8. If any Veteran talks about suicide, **take it seriously** and seek help immediately. The Veterans Crisis Line is 1-800-273-8255 (Press 1 for Veterans).
9. Don't forget to pay attention to your own needs. Visit your doctor regularly, and get plenty of rest so you can stay strong. Your health is essential to your ability to keep providing for the Veteran you care for.



I have more questions. Where can I go for help?

VA knows that being a Caregiver can be both rewarding and hard. You can always find more information at www.caregiver.va.gov, including contact information for the VA Caregiver Support Coordinator nearest you.

You can also call VA's Caregiver Support Line
toll-free at 1-855-260-3274.

The Caregiver Support Line is open
Monday through Friday, 8:00 am – 11:00 pm ET,
and Saturday, 10:30 am – 6:00 pm ET.

Call to talk to caring professionals who can:

- Tell you about the assistance available from VA.
- Help you access services and benefits.
- Connect you with your local Caregiver Support Coordinator at a VA Medical Center near you.
- Just listen, if that's what you need right now.



Wounded Warriors: Their Last Battle Facilitator's Guide for Grief Work with Veterans' Families

Deborah Grassman's presentation, "Wounded Warriors: Their Last Battle" has dramatically and almost singlehandedly increased awareness of Veterans and their unique end-of-life issues in both VA and the community. Not only has Ms Grassman given this presentation to dozens of audiences across the country, a DVD has been widely distributed to VA and community healthcare providers as an effective teaching tool. Although the presentation focuses on Veterans and the impact military service has had on their life and impending death, it also contains **insights into the family's experience and offers perspectives for understanding how these experiences can impact on and often complicate grief and bereavement.**

The questions posed in this facilitator's guide are meant to help Bereavement Directors and Coordinators use the "Wounded Warriors" DVD as a point of departure for exploring issues faced by the families of Veterans with hospice staff and volunteers. The DVD can be viewed in segments or in its entirety followed by a facilitated discussion using some or all of the questions in the Guide. If the DVD is not available, see the resource list at the bottom of this document for alternate sources of materials that can be used in its place.

This Guide was developed by a workgroup of the National Hospice and Palliative Care Organization's (NHPCO) Veterans Advisory Council (VAC) and is part of a series of materials and resources produced for hospice and other healthcare providers in the community. The workgroup is constantly seeking to improve and update all of these resources and would like to hear from you about this Guide:

- How you have used it
- How effective it is
- How easy it is to use
- Suggestions for improving it

Please send your comments to NHPCO at Veterans@nhpco.org.

Wounded Warriors: Their Last Battle

Facilitator's Guide for Grief Work with Veterans' Families

Veteran's Military Experience

- **How has the Veteran's military experience been acknowledged by his or her family? the community? society?**
- **How might this have an impact on the Veteran prior to his or her death or on the bereavement of the family following the Veteran's death?**

Personal Growth

Military service may promote personal growth and self-actualization in the Veteran thus producing a positive outcome for the Veteran/family in terms of improved education, socio-economic status, and upward mobility. Acknowledgement of these aspects of the service experience can have a positive impact on **caregiver/family members' grief/bereavement** in numerous ways.

Period of Service

The specific war/conflict during which the Veteran may have served (i.e., WWII, Korea, Vietnam, Gulf War, OEF/OIF) and its perceived community acknowledgement, (positive or negative), may impact a **Veteran/caregiver's sense of personal shame/pride** and influence their grief/bereavement.

Medals, Awards, Commendations

A Veteran may not seem inclined to talk about his or her military service, but there may be some non-verbal clues such as displayed metals, commendation letters, awards, and unit photos in the home. These mementos afford an opportunity to engage the Veteran/caregiver in a dialogue about their experiences, especially in the presence of stoicism or guardedness.

A deceased Veteran's military service may embody an intergenerational family tradition and be viewed by the bereaved as a badge of honor. Given praise and accolades by others could impact their grief/bereavement by validating or invalidating their feelings.

Veteran's Symptoms

Dynamics such as detachment, psychic numbing, or other symptoms of PTSD demonstrated by the Veteran may have had a profound impact on caregivers or family members and perhaps caused them to fear expression of thoughts and feelings about the Veteran's status. This behavior might translate into avoidance or suppression of these issues in bereavement.

Family Member/Caregiver's Experience of Grief

- **How is the experience of grief at end of life both similar and different for Veterans and non-Veterans?**

Stoicism

Veterans are notorious for their stoicism. Families coping with the effects of PTSD on a loved one can also be stoic and fail to show their feelings externally, often "stuffing" them.

Sense of Helplessness

The process of grieving may be compromised and/or complicated by high levels of stress. For a patient who has experienced traumatic events, the dying process may trigger a sense of helplessness. The bereaved caregiver who may have coped over time with the loved-one's **mental health issues related to experienced trauma**, may find that they also are vulnerable to feelings of helplessness. Veterans and their caregivers may be particularly at risk.

Acceptance and Letting Go

Acceptance and letting go at the end of life will be **impacted by the patient's life experience, including vulnerability to and survival of traumatic events and situations**. The need to remain in control may contribute to decisions that challenge therapeutic goals and **treatment recommendations intended for the patient's benefit**. For Veterans, this "trained-in" directive not to let down their guard may compete with and complicate caregiving and can cause frustration for both family and professional.

Absence and Estrangement

When a patient has been separated from home and family, anger may be present when a family is called upon to provide **care for "someone who was never around to care for us."** Veterans, due to the nature of being "called away" to serve and long posts away from family, may be particularly affected by this issue.

Difficult relationships

At the end of life, if the patient has a history of being abusive in their relationships, they may experience a host of emotions such as shame, guilt, abandonment, regret, fear of retribution, etc. Complicating this picture may be the feelings experienced by the family providing care, possibly as the formerly abused. Sometimes the reunion of the patient and family is for the sole purpose of providing end of life care. This kind of stress in relationship may be true for both Veterans and non-Veterans.

**Service Related
Illness & Death**

This situation is Veteran-specific. The grief experience may be impacted if death is experienced as a result of injury/illness associated with the Veteran’s military **service “service connected” (i.e. cancers following exposure to Agent Orange during Korea and Vietnam, ALS and service during the Gulf War).**

**Perceived Lack of
Care**

In general, caregivers/family may grieve with anger towards the institutional caregivers whom they perceive as unsupportive. For the caregivers of Veterans, this anger **may focus on the “government” and the lack of support to which they believe the Veteran was “entitled”** but did not receive.

Delayed Grief

Grief may be delayed for multiple reasons, including legal proceedings, illness, multiple losses, etc. Delayed grief may place the bereaved in the position of needing social and emotional support at a time when others are no longer prepared to provide that support. For spouses of deceased Veterans who have experienced time without the Veteran as part of their military life, intense grief may begin only after a time beyond the longest period of deployment.

PTSD: Veteran’s Experience & Family’s Experience

- **How might a family’s coping over the years with the Veteran’s PTSD affect the family/caregiver’s grief experiences?**

Loss of the “person”

Sometimes loved ones express that they lost a part of the Veteran in the war. The grief may be expressed not only for the loss of this "changed" person but also represent an end to the hope of ever regaining the "whole" person. They may feel like they no longer had a mother or a brother after he/she returned from battle/combat or their military experience.

Guilt

Might there be added regret or guilt over words spoken, or those left unspoken, due to the strain that PTSD placed on relationships?

Anger

There may be anger at the government, at society, at themselves, or towards the Veteran for experiences suffered because of the war.

Relief? Guilt? Shame?

Might there be relief because they no longer have to shoulder the burden of the Veteran’s PTSD? Such a reaction might trigger shame or guilt for having such feelings.

Unknown Veteran stories

Stories that family didn't know, or perhaps didn't attempt or want to know, may surface at the end of a Veteran's life, leaving the family with questions about why they didn't know and/or why the Veteran never shared the stories with them. These stories may spark a wide range of feelings, such as guilt, remorse, anger or betrayal, especially in the absence of the Veteran.

Death at Home or in a Community Nursing Home

- **In the video, the Veteran dies in a VA facility. How might dying at home or in a community nursing facility affect both anticipatory mourning and bereavement following the death?**

Death at home or in community nursing home

Veterans who have used the VA healthcare system for much of their care throughout their illness may feel an acute sense of loss or even abandonment if/when their care is shifted to home or in a nursing home. Receiving care outside of the VA system often means that the Veteran will no longer see or interact with his or her VA healthcare providers and fellow comrades.

It is possible that community caregivers, such as hospice agencies and nursing homes, may not know a lot about the health, psychosocial and emotional issues that are unique to Veterans. They also may not understand the importance of military rituals and honors, which often take on more meaning at the end of life. This lack of knowledge may interfere with life closure activities, anticipatory grieving and bereavement following death.

Perceived loss of support

Families, especially non-Veteran family members, will likely experience a loss of support accompanied by loss of access to a system that has been a major part of their lives, perhaps for most of their adult lives.

Loss of Benefits

Families may be concerned that they will lose benefits if they don't stay connected to the VA system.

VA System: Benefits & Support. Veterans want to make sure their families have adequate resources after they die

- **How can we help families/caregivers use the VA system for access to both benefits and emotional support?**

Military History Checklist

Use the military history checklist to identify Veterans and family members of Veterans

VA Benefits	<p>The single largest concern for the families of Veterans, especially those who have used the VA system, is that community hospices do not understand their benefits or know how to help them access those benefits.</p> <p>Support for survivors begins early in the process by having an understanding of the relationship between the patient/family, the VA and the benefits to which they are entitled.</p>
VA Benefits Counselor	Every VA Medical Center has a Benefits Counselor and a Decedent Affairs Counselor who can help with both benefits and burial needs.
VA Hospice Benefits	VA hospice services are part of the Basic Medical Services package. All Veterans can access the VA Hospice Benefit if they are enrolled with the Veteran Health Administration; enrollment usually can be expedited if the Veteran is eligible for hospice services and is not yet enrolled.
VA Mental Health Counselors	VA Medical Centers have Mental Health counselors and Suicide Prevention Coordinators available to provide counseling services for enrolled Veterans.
State & County Veterans Service Officers	Every state has county or municipal Veterans service officers. Most communities have Veterans Service Organizations (VSOs) such as the American Legion, Paralyzed Veterans of America, and Disabled American Veterans that can help families advocate for benefits to which the Veteran/family may be entitled.
Vet Centers	Vet Centers offer counseling services for all Veterans and their families, regardless of enrollment status
National Cemeteries	Many times both Veterans and their family members want a military burial or may want to access burial benefits available to the Veteran. Community hospice providers can do a great service and provide enormous comfort by having some knowledge of these resources and being able to support the family member in accessing them. Go to www.cem.va.gov for more information. Hospice providers can also contact the Decedent Coordinator at the nearest VA Medical Center or the County Veterans Service Officer for assistance.
VA Resources for Community Agencies	Resources are available to help community hospice providers learn about Veteran benefits
We Honor Veterans	A program of the National Hospice and Palliative Care

Organization, **We Honor Veterans** has many resources, including the Military History Toolkit, posted at www.WeHonorVeterans.org.

Resources

"Wounded Warriors: Their Last Battle", the video. Email Veterans@nhpco.org.

"Wounded Warriors: Their Last Battle" slide set is available on the Hospice and Palliative Care Federation of Massachusetts website:
http://www.hospicefed.org/hospice_pages/education.htm

Boss, P. (1999) *Ambiguous Loss – Learning to Live with Unresolved Grief*. Harvard University Press, Cambridge, MA.

Grassman, D. "Wounded Warriors: Their Last Battle", Home Healthcare Nurse. 25(5): 299-304, May 2007.

Grassman, D. *Peace at Last: Stories of Hope and Healing for Veterans and Their Families*. Vandamere Press, P.O. Box 149, St. Petersburg, FL 33731. (To order from within the United States, please call 800-551-7776. To order from outside the United States, call 727-556-0950 or email orders@vandamere.com).
www.vandamere.com/peace.htm

Process of Enrollment of Hospice Veterans for VA Care: Catastrophically Disabled Evaluation

VHA Directive 2004- 067



VHA DIRECTIVE
2004-067 CATASTRO

Step 1: Identification of veteran using Military History Checklist



MILITARY HISTORY
CHECKLIST- 6 QUEST

Veteran is *not* enrolled in the VA and would like to get enrolled: **YES**

Step 2: Referring provider obtains medical information for completion of Catastrophically Disabled Evaluation

Meets *one* of the criteria:

- Dependent on **3 or more** ADLs using **Katz Index of Activities of Daily Living**



KATZ INDEX ADL.pdf

- Score of **10 or lower** using **Folstein Mini Mental State Exam (MMSE)**



MMSE.pdf

- Score of **2 or lower** on at least **4** of the **motor items** using the **Functional Independence Measure (FIM)**
- Score of **30 or lower** using the **Global Assessment of Functioning (GAF)**

Step 3: Referring clinician provides the following information to VA Point of Contact

Medical Information

Functional evaluation

Military Discharge papers (DD-214)

To request copy of DD-214 need form SF 180 of file online at:

<https://vetrecs.archives.gov/VeteranRequest/home.asp>

Army Veterans discharged or deceased between Nov 1912 and Dec 1959 or
Air Force before January 1964 whose name comes alphabetically after Hubbard
Records may have been lost in a fire and you will also need NA Form 13075

Demographic information

Step 4: VA clinician completes VA Form 10-0383 Catastrophically Disabled Evaluation & Enrollment Approval Request



VHA FORM
CATASTROPHICALLY

Step 5: VA Point of Contact submits VA Form 10-0383
to VA Medical Center Chief of Staff/ Designee for approval

Facility approval: **YES**

Step 6: VA Eligibility Clerk enrolls Veteran into VA system

Goal: Hospice Veteran is enrolled and is eligible to receive VA services

Tomah VA Fact Sheet for Hospice Partners



Tomah VA Medical Center

500 E. Veterans St. Tomah, WI 54660

Phone number (608) 372 -3971

Website: <http://www.tomah.va.gov/>

Brief description of palliative and hospice care program:

21 bed Hospice/Palliative Care Unit

Palliative Care Consultation team available for all inpatients and HBPC patients

Outpatient Palliative Care Clinic upon request on main campus

Service Area:

Tomah VAMC covers the Southwestern Wisconsin area into Southern Minnesota and northern Wisconsin from Wausau to Tomahawk, WI.

Community-Based Outpatient Clinics- In addition to our main facility in Tomah, we offer services in four community-based outpatient clinics.

These clinics are located in:

- ★ La Crosse
- ★ Loyal
- ★ Wausau
- ★ Wisconsin Rapids
- ★ Clark County Clinic- Owen, WI opening September 2011

Palliative Care Coordinators: name, title or both; phone number; fax; email

Inpatient Hospice/Palliative Care:

Maureen Juracich BSN RN

Phone: 608-372-1752

Email: Maureen.Juracich@va.gov

Home Hospice Coordinator:

Maria Babcock BSN RN

Phone: 608-372-1102

Email - Maria.Babcock@va.gov

PTSD Resource:

Cathy Komiskey

PTSD Residential Rehabilitation Program (PRRP) Intensive/Inpatient

cathy.komiskey@va.gov

(608) 372-3971 X 66437

Homeless Coordinator:

Cindi Groskreutz, LICSW, BCD

VA Grant and Per Diem Liais

Direct Phone- 608-372-7768

Homeless staff cell phone- 608-567-1199

Caregiver Support Coordinator:

Danielle Olson, LCSW, ACSW

Caregiver Support Coordinator

Tomah VA Medical Center

500 E. Veteran Street

Tomah, WI 54660

608-372-1229

Vet Center:

La Crosse Vet Center

20 Copeland Ave.

La Crosse, WI 54601

Phone: 608-782-4403

Fax: 608-782-4423

Key Staff:

Joseph J Huth- Team Leader

Megan L Jones- Office Manager

Norbert B Laufenberg- Family Therapist

Kari C Stetzer- Counselor

Robert J Thoen- OEF-OIF Outreach Specialist

Madison VA Fact Sheet for Hospice Partners



William S. Middleton Memorial Veterans Hospital

2500 Overlook Terrace

Madison, WI 53705

Phone number (608) 256-1901

Website: <http://www.madison.va.gov/>

Brief description of palliative and hospice care program:

Inpatient Consultation:

- Assistance with complex medical decisions
- Assistance with complex pain and symptom management
- Establish a Veteran-centered plan of care
- Provide emotional and spiritual support
- Discharge planning

Outpatient Clinic:

- Ongoing management of complex pain and other symptoms related to the life-limiting condition
- Timely information about how to best plan for future care needs
- Assistance in locating and arranging services as care needs change
- Ongoing psychosocial and emotional support

Hospice/Palliative Care Beds

Service Area:

The Madison VA Hospital covers the South Central Wisconsin and Northern Illinois

Community-Based Outpatient Clinics- In addition to our main facility in Madison, we offer services in several community-based outpatient clinics.

These clinics are located in:

- ★ Madison-west side
- ★ Janesville
- ★ Beaver Dam
- ★ Baraboo
- ★ Janesville
- ★ Rockford, IL
- ★ Freeport, IL

VA Madison Inpatient Palliative Care:

Sheila Schroedl, LCSW

Phone: 608-256-1901 x11579

Email: sheila.schroedl@va.gov

VA Purchased Community Care Coordinator:

Tim Latimer

Phone: 608-280-7247

Email – tim.latimer@va.gov

Homeless coordinator:

Jennifer White, MSSW

VA Homeless Program Grant and Per Diem Liaison

Phone- 608-280-2095 x16420

Caregiver Support Coordinator:

Jennifer Jaqua, LCSW

Phone: 608-256-1901 x11485

Email: Jennifer.jaqua@va.gov

Vet Center:

MADISON VET CENTER

Central Region, Vet Center #419

706 Williamson Street, Suite 4

Madison, Wisconsin 53704

Phone: 608/264-5342

Fax: 608/264-5344

Milwaukee VA Fact Sheet for Hospice Partners



Clement J. Zablocki, Milwaukee VA Medical Center

5000 W. National Ave.

Milwaukee, WI 53295

Phone number 414-384-2000

Brief description of palliative and hospice care program:

24 bed Hospice/Palliative Care Unit

Palliative Care Consultation team available for all inpatients

Service Area:

VAMC Milwaukee serves veterans from the Wisconsin, Minnesota, Northern Illinois areas.

Community-Based Outpatient Clinics-

In addition to our main facility in Milwaukee, we offer services in community-based outpatient clinics.

These clinics are located in:

- ★ Appleton
- ★ Cleveland
- ★ Green Bay
- ★ Union Grove

Palliative care coordinators:

Inpatient Hospice/Palliative Care: Trisha O'Leary, LCSW
Phone: (414) 384-2000 ext. 46742
Email: Trisha.Oleary@va.gov

Home Hospice Coordinator:
Social work staff—
Trisha O'Leary can be contacted for assistance
Phone: 414-384-2000 ext. 46742
Email – Trisha.Oleary@va.gov

PTSD resource:

Dr. Karen Berte
PTSD Coordinator
Karen.Berte@va.gov
(414) 384-2000 ext. 41669

Homeless coordinator:

Barbara Gilbert, LCSW
Homeless Veterans Coordinator
Barbara.Gilbert@va.gov
(414) 342-2224

Caregiver Support Coordinator:

Kevin Thomsen, CICSW
Caregiver Support Coordinator
Kevin.Thomsen@va.gov
(414) 384-2000 ext. 45980

Vet Center:**Milwaukee Vet Center**

5401 N. 76th St., Suite 100
Milwaukee, WI 53218

Phone: 414-536-1301
Fax: 414-536-1568

Green Bay Vet Center

1600 S. Ashland Ave
Green Bay, WI 54304

Phone: 920-435-5650
Fax: 920-435-5086

Iron Mountain VA Fact Sheet for Hospice Partners



Oscar G. Johnson VA Medical Center

325 East H Street

Iron Mountain, MI 49801

Phone number (906) 774-3300

<http://www.ironmountain.va.gov/>

Brief description of palliative and hospice care program: Inpatient Palliative care contacts: Selena Okler, RN, Palliative Care Coordinator Extension 34504 selena.okler@va.gov Patricia Staller, LMSW, Extension 34514 Bob Peterson, NP, 34515 fax number for inpatient referrals: 1-906-779-3146

Home care coordination/Home hospice: Lisa Patterson, RN 32570 or Stacy Matson, RN 32563
Fax number for outpatient home care or hospice referrals: 1-906-779-3112

Service Area: The organization provides primary care at the Oscar G. Johnson VA Medical Center as well as at clinics in Hancock, Menominee, Marquette, Ironwood, Sault St. Marie, Michigan; and Rhinelander, Wisconsin. Over 33,000 veterans in the Upper Peninsula of Michigan and northeastern Wisconsin rely upon the Oscar G. Johnson VA Medical Center and Clinics for their health care.

PTSD resource: Gail Beauchamp, LMSW, Behavioral Health Service; Extension 32712

Homeless coordinator: Nicole Foster-Holdwick, LMSW, Behavioral Health Service; Extension 31221

Competency: Hospice and Palliative Care for the U.S. Veteran

Name _____ Title _____ Department _____

* 1 = fully competent 2 = knowledgeable, but needs practice 3 = needs review Last Review: _____

Competency	* Self-Assessment	Learning Activities/Options	Method of Evaluation	Date Met/Signature of Validator
<ul style="list-style-type: none"> • Identifying the hospice or palliative care patient as a veteran as part of the team's admission assessment and its importance in the plan of care for the veteran. • Questions that can be used to begin the military history and help identify issues of concern. ▪ The Impact of the unique issues of different wars on the mental and physical state of the veteran. ▪ Post Traumatic Stress Disorder(PTSD) and its signs and symptoms and treatment. ▪ Relationship between the Veteran's Administration and local hospices. ▪ Recognition and honoring the veteran's service to their country. 		<p>Review of Team Assessment.</p> <p>PowerPoint presentation "The Unique Needs of Veterans at the End of Life."</p> <p>Military History Pocket Card</p> <p>Discussion with preceptor.</p> <p>PowerPoint presentation "The Wounded Warrior" By Deborah Grassman.</p> <p>Fast Fact Concept #152 "The Military History as a Vehicle for Exploring End of Life Care with Veterans"</p> <p>Article "Treating the Veteran with PTSD at End-of-Life"</p> <p>Article "VA Transforms End of Life Care for Veterans"</p> <p>HOPE Hospice/Veterans Toolkit</p>	<ul style="list-style-type: none"> ▪ Successful completion of test ▪ Demonstrates obtaining a military history and can verbalize unique issues of different wars and the impact on the veteran. ▪ Demonstrates/verbalizes how to identify Post Traumatic Stress Disorder and helpful interventions. ▪ Can name contacts in the community and VA facilities that can help facilitate veterans needs. ▪ Demonstrates/verbalizes the benefit of recognition of the veterans service to our country and how this might be accomplished 	

<p>Hospice and Palliative Care for the U.S. Veteran</p> <p>Competency statement: The purpose of this competency is to provide the learner with the knowledge and skills to identify the hospice and palliative care patient who is a veteran and its impact and importance on the plan of care.</p> <p>Education resources: PowerPoints “Unique Needs of Veterans at the End of Life” and Deborah Grassman’s “The Wounded Warrior”, “Military History” pocketcard, “Fast Fact Concept #152 “The Military History as a Vehicle for Exploring End of Life Care with Veterans”, journal article “VA Transforms End of Life Care for Veterans”, and “Treating the Veteran with PTSD at End of Life” and HOPE Hospice/Veterans Toolkit. Post Test.</p>	<p>Name: _____</p> <p>Date Completed: _____</p>	
<p>BEHAVIORAL CRITERIA</p>	<p>VALIDATOR INITIALS / DATE</p>	<p>COMMENTS</p>
<p>Can verbalize how and when the veteran is identified as part of the admission assessment and how this may impact the plan of care.</p>		
<p>1. Referral Assessment asks “Are you a veteran?” and “Are you registered with the VA?” This will alert the RN and SW to explore the veteran service with the patient and encourage registration with the VA as desired.</p> <p>2. SW admission assessment explores the veterans experience with the questions “Did you see combat?” “What was that, or your military experience like for you?” “Is there anything about your military experience that is still troubling you?” .</p> <p>3. RN or SW includes facts regarding military service in the plan of care. Referrals are made to the County Veteran Service Officer or Regional VA facility.</p> <p>4. Materials to read and reference are in the Education file on the Hospice Server under “Hospice and Palliative Care for the U.S. Veteran Competency”.</p>		
<p>Can list unique issues of different wars and their impact on the veteran and their plan of care.</p>		
<p>1. World War II 1941-1945</p> <ul style="list-style-type: none"> • Supported by virtually everyone. • Came home to a heroes welcome. • Fought in several countries in extreme climates and circumstances. • May need to give voice to atrocities of war as they were not talked about. America wanted “victory”. <p>2. Korean War 1950-1953</p> <ul style="list-style-type: none"> • Often called “The Forgotten War”. • Solders fought in extreme weather conditions. • Ended in a stalemate. • Soldier’s efforts minimized, traumas ignored. 		

<p>3. Vietnam War 1964-1975</p> <ul style="list-style-type: none"> • Unpopular war with much anti-war sentiment at home. • Guerilla war tactics—enemy could be anyone. • A war without a victory. Soldier felt disrespected, shamed, and disregarded. • Soldiers buried their stories. PTSD, survivor guilt, effects of Agent Orange. <p>4. Desert Shield/Desert Storm/Operation Iraqi Freedom.</p> <ul style="list-style-type: none"> • Recently acknowledged that some veterans have experienced Military Sexual Trauma and is now a recognized treatment focus. • PTSD and Traumatic brain injury frequent. • Many women now serving in combat zones. 		
<p>Can identify characteristics Post Traumatic Stress Disorder and helpful interventions</p>		
<p>1. Some people who did not previously have symptoms may experience delayed onset at the end of life.</p> <p>2. Some symptoms may be: hypervigilance, irritability, insomnia and exaggerated startle response and distrust.</p> <p>3. Triggers may be pain, helplessness, fear, anxiety, decreased functional status.</p> <p>4. In some people who are accustomed to feeling tense, the sensation of relaxation may paradoxically create discomfort and anxiety. Use of anti-anxiety agents may trigger increase in symptoms.</p> <p>5. Helpful interventions may include:</p> <ul style="list-style-type: none"> • Asking what triggers symptoms and avoid it. • Avoid sudden, unannounced, loud noises when possible. • Verbally cue in advance before touching. • Avoid arousing by shaking or yelling. Stand at the foot of the bed and call veteran’s name. • Assist as possible in retaining autonomy and control. • If the veteran has a flashback in your presence, stay calm, call their name and state who you are and what you are doing. • Ask what helps and comply if possible ie nightlight, more privacy, announced approach. 		
<p>Can provide contacts in the community and VA facilities that can help the veteran.</p>		
<p>1. Veteran’s Administration website will have helpful information.</p> <p>2. Refer to the Social Worker who can investigate resources such as the County Service Officer or contact person at each VA Facility.</p>		

Can assist in helping the veteran with life review and providing the veteran recognition to facilitate healing.		
<ol style="list-style-type: none">1. Listen patiently and warmly, and allow them to stop when they are ready..2. Avoid attempts to comfort that stifles the topic and expression of feelings. (“It’s ok”, “That was a long time ago.”)3. Inform them that it is expected to have memories at the end of life, good as well as bad.4. Refer to chaplain or social worker or VA consult as needed.5. Offer a volunteer who has served in the military if available.6. Discuss with the Team giving a certificate that honors their military service and a “Thank you for serving our country”.		



NHPCO awards Veterans Outreach Grant

The National Hospice and Palliative Care Organization (NHPCO) has selected Hope Hospice and Palliative Care in Medford and the Tomah and Madison Veteran Administration Medical Centers as one of five recipients in the United States to receive a “Reaching Out” grant to help meet the needs of rural and homeless veterans. Grant reviewers from the field evaluated forty proposals submitted to NHPCO.

This grant will be carried out along with Palliative Care Coordinators Jolene Renda, DNP ANP/CNP at the Veterans Administration Hospital in Tomah and Sheila Schroedl, LCSW at the Veterans Hospital in Madison and Teri Rostberg, Executive Director of Hope Hospice and Palliative Care in Medford Wisconsin. This \$34,000 grant will enable Hope Hospice and the veteran facility partners to build upon the work we have done with the Hospice and Palliative Experts of Wisconsin Hospice-Veteran Partnership to advocate for veterans with life-limiting or chronic health needs.

“As a member of the steering committee for the Hospice-Veteran Partnership, we have worked to pull together training materials to increase awareness of hospice and end of life issues for veterans, exchange information with VA medical centers to provide needed information about hospices in the state and to educate hospice staff about the unique needs of veterans and their families”, explained Teri Rostberg, Executive Director of Hope Hospice. “The members of the steering committee have benefited from sharing materials and making connections between hospice agencies and VA facilities to enhance communication when individual patient issues arise.” Through this grant, Hope Hospice and its VA partners will extend the availability and usefulness of these materials by putting them into DVD and audio CD formats. The purpose of the grant is to expand the awareness of end of life issues and the unique needs of veterans and their families to those agencies such as emergency rooms, first responders and aging and disability resource centers and others that may have contact with rural and homeless veterans.

Nearly 40 percent of enrolled veterans live in areas that are considered rural, where a variety of community services and VA palliative care programs are often not readily available. Ensuring that all veterans receive compassionate, quality care at the end-of-life is a priority of Wisconsin Hospices, NHPCO and the Department of Veterans Affairs Hospice and Palliative Care Program. Projects in other states have learned through veteran focus groups that fewer than half surveyed knew the benefits of hospice care or even that hospice care was available to them through the VA healthcare benefit.

Hospice care is part of the basic eligibility package for veterans enrolled in the Veterans Health Administration (VHA). Hospice services also are covered by Medicare, Medicaid, and private insurance plans. However, like majority of the American public, most veterans don’t know that these options exist.

“These grants serve a two-fold purpose,” said J. Donald Schumacher, NHPCO president and CEO. “They support specific, community-based programs and the lessons learned will help the VA in discovering new ways to reach veterans who are homeless or living in rural areas and in need of quality care as they near the end of life.” Funded through a contract with the Department of Veterans Affairs, the Reaching Out grants were created to support innovative programs committed to increasing access to hospice and palliative care for rural and homeless Veterans.

Rural and Homeless Veteran Outreach

Would you recommend this presentation to others? _____ Yes _____ No Why or why not?

Would you change anything about where the presentation was held? _____ Yes _____ No

Would you change anything about the presentation materials _____ Yes _____ No

Comments _____

What other topics would you like to have presented?

Comments _____

Please rank the following presentations (1 lowest, and 5 highest)

Veterans Information-	1	2	3	4	5
Homeless Information	1	2	3	4	5
Hospice and Palliative Care Information	1	2	3	4	5
Advance Directives	1	2	3	4	5
Information on PTSD	1	2	3	4	5
Competencies for staff training	1	2	3	4	5

How did you hear about this workshop? _____

Thank you

Please send comment to:

Teri Rostberg,
 Hope Hospice
 537 W Broadway
 Medford WI 54451
 hhospice@newnorth.net
 Phone: 715-748-3434
 Fax: 715-748-1268 fax

