

*Traumatic Brain Injury: A Guide for Caregivers
of Service Members and Veterans*



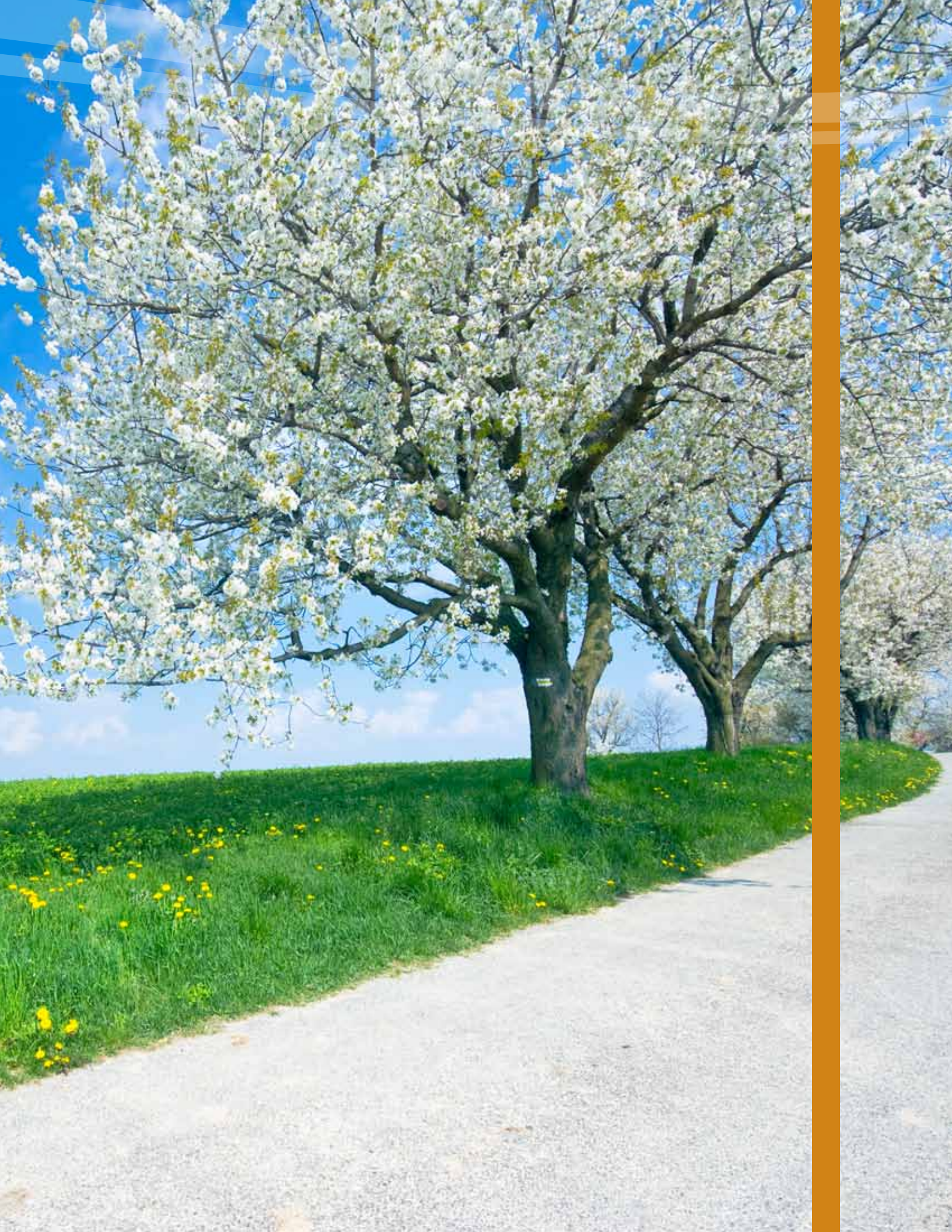
Welcome



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*An electronic version of this Guide can be found at the following Web address:
www.traumaticbraininjuryatoz.org*





Welcome

“There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

- Former First Lady Rosalynn Carter

Traumatic brain injury (TBI) is a major public health problem in the United States. In 2006, the Centers for Disease Control and Prevention reported that TBI is more prevalent than cases of multiple sclerosis, HIV/AIDS, and breast cancer combined. Due to the present conflicts in Iraq and Afghanistan, members of the United States Armed Forces are one of the largest populations at risk for TBI. Of the service members medically evacuated for battle-related injuries from Iraq and Afghanistan to Walter Reed Army Medical Center, 33 percent had traumatic brain injury (as of March 2009). Due to medical and technological advances, we have seen a decrease in mortality rates for those with severe TBI from the 50 percent range in the 1970s to the 30 percent range at this time. As a result, family members and loved ones like yourself are increasingly being recruited to enlist in the ranks of caregivers to assist in the journey toward the greatest level of recovery possible for your service member. This guide was written to support and empower you along this journey.


Individuals who sustain a TBI may experience short- and long-term effects, such as alterations in thinking, sensation, language, behavior, and emotions. Whether the TBI is mild, moderate, or severe, persistent symptoms can have a profound and persisting impact, not only on the injured survivor but also on those who function as caregivers. It is you, the caregiver, who must not only survive the immediate shock when a TBI occurs, but must also learn to support and aid the service member who experiences ongoing effects caused by this injury. A TBI can radically change the lives of the individuals who are closest to those who experience it.

In December 2006, Congress took action to support caregivers by passing the National Defense Authorization Act of 2007. Section 744 of this act mandated the development of “...coordinated, uniform, and consistent training curricula to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with traumatic brain injuries.” This curriculum, *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*, is the product of this mandate.

The Defense and Veterans Brain Injury Center (DVBIC) received this Congressional mandate on 23 April 2007. DVBIC was tasked with providing programmatic and logistical support to develop the curriculum according to the Congressional mandate, ensure content accuracy, and both implement and maintain the curriculum into the future. DVBIC was selected because of its nearly 20 years of service to active duty military, their beneficiaries, and veterans with traumatic brain injuries. We fulfill our mission through ongoing collaboration with military, Department of Veterans Affairs (VA), and civilian health partners, local communities, families, and individuals with TBI, utilizing best medical evidence to optimize care from the battlefield to the community.

Ms. Ellen Embrey, Acting Principal Deputy Assistant Secretary of Defense for Health Affairs, commented that, “We are absolutely committed to providing the best information found in sound science and based on medical evidence. We want the Traumatic Brain Injury Family Caregiver curriculum to be the authoritative source of information and support for family caregivers of service members with TBI. This is another step we are taking to ensure that those who protect our country and our freedoms are also protected.” Ms. Embrey also added that, “Information is a powerful tool. We must remain proactive in providing deployment-related health information to better safeguard our service members. Most people fear the unknown. Through accurate, timely information, we are able to ensure that our service members are better equipped to prepare for, cope with, and recover from the myriad health risks faced during deployments.”

This Guide was designed to empower you by offering a uniform source of information while instilling hope as you navigate life after TBI. We have made every effort to make this an accurate and informative tool that is user-friendly and based on the needs of real-life caregivers and their experiences. Our goal is not only to give you the information you need, but also to offer reassurance and guidance as you set forth on this journey. You have been thrust into a new reality where you are asked to be the voice, ears, and eyes of your wounded warrior. You must all-at-once act as an advocate, counselor, and nurse, all the while striving to maintain your role as mother, father, husband, wife, son, daughter, sister, brother, and/or friend. Those around you watch and marvel as you willingly confront this challenge with courage, integrity, and a defiant spirit.



I want to thank you, the caregiver, for your service to our country. We will always be indebted to you and your service member for your courage and sacrifice.



Col Michael S. Jaffee, MD

National Director
Defense and Veterans Brain Injury Center

“There are two ways of spreading light -- to be the candle or the mirror that reflects it.”

- Edith Wharton

A Message from the Traumatic Brain Injury Family Caregiver Advisory Panel

Welcome to *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*. Traumatic brain injury (TBI) experts, survivors, and experienced caregivers, along with representatives from the Department of Defense, the Department of Veterans Affairs, and organizations that support the military were members of the TBI Family Caregiver Advisory Panel, which oversaw the development of this Guide.

The purpose of this Guide is to provide you, the caregiver, with the information you need to care and advocate for your injured loved one and to care for yourself in the process.

Just as no two individuals are alike, no two brain injuries are identical. It is impossible to determine the speed and extent of recovery in the immediate aftermath of TBI. Throughout the recovery process, there are likely to be many steps forward and perhaps a few steps back. Time and treatment will lead to an optimal level of recovery. We hope this Guide will sustain you along the way and allow you to identify and access the information and support you need and deserve.

Being a caregiver can be both challenging and rewarding. During the development of this Guide, caregivers repeatedly shared that what helped them the most was taking each day one at a time, learning to ask for and accept help, taking steps to reduce stress, and maintaining hope.

We are honored to have taken part in the creation of this resource designed specifically for you, the caregiver. Our hope is that it will provide you with information when you need it and a voice of support and encouragement for the journey ahead. As a caregiver you have earned the enormous respect of the TBI Family Caregiver Advisory Panel. We would like to express our sincere appreciation and gratitude for the military service of your distinguished veteran or service member and for your own unique contribution to our country.

Wishing you the very best.



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- Nellie B., Army National Guard parent, whose son José (a former Marine) experienced a severe TBI in Iraq when a grenade exploded behind him.
- Liza B., TBI Family Caregiver Panel member and Army family member, whose brother Ethan suffered a severe TBI from sniper gunshot.
- Lynn C-S., Army wife, whose husband Patrick was injured on two separate occasions by improvised explosive devices (IEDs).
- Cyd D., Marine Corps parent, whose son Adam suffered three separate blasts in Iraq, the last of which was when a rocket-propelled grenade (RPG) hit his machine gun post.
- Anna E., Marine Corps wife, whose husband Ty sustained a sniper gunshot wound to the head while leading an embedded training team in Afghanistan.
- Pam E., Army parent, whose son Jason was injured in Baghdad when an IED exploded in the Humvee where he was gunner.
- Denise G., Air Force wife, whose husband Fred, a Colonel, is now medically retired following a brain injury.
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- Shannon M., TBI Family Caregiver Panel member and Marine wife, whose husband Tim took shrapnel wounds to the head from a mortar attack in Iraq.
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We also extend a special thank you to the dedicated caregivers who participated in focus groups held throughout the country. The feedback from these real-life caregivers helped make this Guide more user-friendly and responsive to the needs of caregivers like you.

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Introduction to the Caregiver's Guide

"I so wish that at the beginning I had had someone like the people I've met here at Fisher House, who are already two years post-injury. I wish I would have had somebody like that come up to me and just put their arms around me and say, 'You know what? Any question you need to ask, just ask it.'"

- Meredith H.



You have started one of the most important jobs in your life—becoming a family caregiver to a service member who has a serious traumatic brain injury (TBI).

The information in this Guide will help you cope with your new role as a caregiver. You will find lots of helpful information here, gleaned from both TBI experts and caregivers like yourself. However, not all of the information may apply to your situation. You can also read this Guide online at www.traumaticbraininjuryatoz.org.

What's in this Guide?

This Guide has information for caregivers of service members/veterans who have a moderate to severe TBI. It contains four modules, plus the Caregiver's Companion:

Module 1: *Introduction to Traumatic Brain Injury.* This module tells you about the brain and what happens when it is injured.

Module 2: *Understanding the Effects of TBI and What You Can Do to Help.* This module explains the physical, thinking, communication, and emotional effects of TBI. It also tells you how you can help your family member deal with these effects.

Module 3: *Becoming a Family Caregiver for a Service Member/Veteran with TBI.* This module is all about you, whether you are a caregiver at home or supporting your family member at a health care facility. It has tips on how to organize your life as a caregiver. It encourages you to take care of yourself during this stressful time.

Module 4: *Navigating Services and Benefits.* This module tells you about how the disability rating system works. It describes how to get services and benefits that can help your family member with TBI.

Caregiver's Companion: The Companion is a binder of information and forms to help you in the day-to-day management of caregiving.

Please learn about TBI—it will help you be a better caregiver. Take good care of yourself while caring for your service member/veteran. Keep hope alive during your journey toward recovery.


How to Use This Guide

The main intent of the Guide is to provide information as you need it. For example:

- You may be most interested in **Module 1**, *Introduction to Traumatic Brain Injury (TBI)*, when you are in the initial phases of your service member's diagnosis and treatment. Module 1 explains TBI with graphics to help you understand the injury and the initial treatment.
- As time goes on, **Module 2**, *Understanding the Effects of TBI and What You Can Do to Help*, will help you during the treatment and recovery phase to understand the many possible ways a TBI may affect your service member. It includes tips on what you can do to help in the treatment and recovery process.
- **Module 3**, *Becoming a Family Caregiver for a Service Member/Veteran with TBI*, will be helpful from the beginning of and throughout your family's journey with TBI. It has suggestions to help you organize all the information you are gathering and guidelines for how to take care of yourself, along with tips for taking care of your service member/veteran with TBI.
- **Module 4**, *Navigating Services and Benefits*, will be a long-term reference for you. It has information on the services and benefits you and your service member/veteran are entitled to. You can use the information in Module 4 to identify your family's needs and to raise questions about needed services with your service member/veteran's Point of Contact.

The four modules are tabbed and color-coded to help you find them easily in the binder:

- Module 1 is yellow.
- Module 2 is blue.
- Module 3 is green.
- Module 4 is red.



The **Caregiver's Companion** has information and forms that can help you in your caregiving journey. You may want to carry it with you to keep track of important information. Use this binder to keep yourself organized. You may need to start a new binder as this one gets full. The Companion includes:

- Master forms to write down key information. The master forms in the Companion, such as the medication log or contact information for members of the health care team, are meant to be duplicated. Make several copies of each to use over time or download the forms from www.traumaticbraininjuryatoz.org.
- Plastic sleeves to keep business cards of medical professionals and others you want to be able to contact later for more information. There are also plastic sleeves for compact disks of medical scans and tests you will want to keep. You may need to purchase more sleeves.
- Basic information, such as a glossary of terms, table of military ranks, list of acronyms, etc.

The entire Guide may also be helpful for other family members and friends to read and understand traumatic brain injury and treatment. The Guide may be instructive for grown children, parents, mothers- and fathers-in-law, and extended family and friends. Suggestions for creative uses of the Guide could include:

- Suggest a family member read a section to understand the specific injury your service member/veteran sustained or to understand physical, cognitive, or behavioral effects of TBI.
- Use the Guide as a conversation starter or a tool in talking with your service member/veteran.
- Use the Guide to provide an orientation for medical professionals who are not specialists in TBI.

Web sites and telephone numbers listed in the Guide are current as of the date of publication. They change frequently; you may need to use a search engine to find the current address for some Web sites.

*There are moments when wellness escapes us,
Moments when pain and suffering
Are not dim possibilities
But all too agonizing realities.
At such moments we must open ourselves to healing.*

*Much we can do for ourselves;
And what we can do
We must do—
Healing,
No less than illness,
Is participatory.*

*But even when we do all we can do
There is,
Often,
Much left to be done.
And so as well we turn to our healers
Seeking their skill to aid in our struggle for wellness.*

*But even when they do all they can do
There is,
Often,
Still much left to be done.
And so we turn to Life,
To the vast Power of Being that animates the universe
As the ocean animates the wave,
Seeking to let go of that which blocks our healing.*

*May those
Whose lives are gripped in the palm of suffering
Open
Even now
To the Wonder of Life.
May they let go of the hurt
And meet the True Self beyond pain,
The Uncarved Block
That is our joyous Unity with Holiness.*

*May they discover through pain and torment
The strength to live with grace and humor.
May they discover through doubt and anguish
The strength to live with dignity and holiness.
May they discover through suffering and fear
The strength to move toward healing.*

- Rabbi Rami M. Shapiro

Excerpted from *Prayers for Healing* ©1997 by Maggie Oman, reprinted courtesy of Conari Press.

Index to the Guide

This index is designed to help you find information quickly and easily. The index covers words or phrases found throughout the Guide in Modules 1, 2, 3, and 4, and in the Caregiver's Companion (listed as Companion). Another way to find information is to read through the Table of Contents of each module.

You will find many acronyms (abbreviation of a phrase) in the index. The most common acronyms are TBI (traumatic brain injury), DoD (Department of Defense), and VA (Department of Veterans Affairs).

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Military Terms Related to Injuries and Treatment

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BI – Battlefield Injury

CASEVAC – Casualty Evacuation

MTF – Medical Treatment Facility; for example:

NNMC – National Naval Medical Center,
commonly called “Bethesda”

NMCS – Naval Medical Center San Diego,
commonly called “Balboa”

BAMC – Brooke Army Medical Center

WRAMC – Walter Reed Army Medical Center

OT – Occupational Therapy

PT – Physical Therapy

PTSD – Post-Traumatic Stress Disorder

SCI – Spinal Cord Injury

TBI – Traumatic Brain Injury

VSI, SI, SPECAT – Very Seriously Injured, Seriously Injured,
Special Category

WII – Wounded, Ill, and Injured

Military Terms Related to Medical Review Boards

- Companion, page 14

COAD – Continuation on Active Duty

COAR – Continuation on Active Reserve

DES – Disability Evaluation System

EPTE – Existed Prior to Entry

HAO – Home Awaiting Orders

MEB – Medical Evaluation Board

MMRB – MOS Medical Retention Board
MOS – Medical Occupational Specialty
PEB – Physical Evaluation Board
PDRL – Permanent Disability Retirement List
PLD – Permanent Limited Duty
TDRL – Temporary Disability Retirement List
VASRD – Veterans Affairs Schedule for Rating Disabilities

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AW2 – U.S. Army Wounded Warrior Program,
formerly called DS3
BAH – Basic Allowance for Housing
BAS – Basic Allowance for Subsistence
CACO – Casualty Assistance Call Officer
CONUS – Continental U.S.
(OCONUS is Outside the Continental U.S.)
DoD – Department of Defense
FMLA – Family and Medical Leave Act
IED – Improvised Explosive Device
ITOs – Invitational Travel Orders
M4L – Marine For Life
MLO – Marine Liaison Office
NMA – Non-Medical Attendant
OEF – Operation Enduring Freedom
OIF – Operation Iraqi Freedom
PNOK – Primary Next of Kin
SSN – Social Security Number
TSGLI – Traumatic Servicemembers' Group Life Insurance
VA – Department of Veterans Affairs
(formerly called Veterans Administration)
VBA – Veterans Benefits Administration
VSO – Veteran Service Officer

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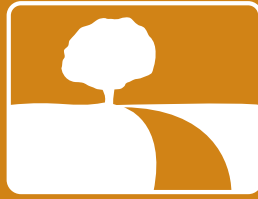
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Notes







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