

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

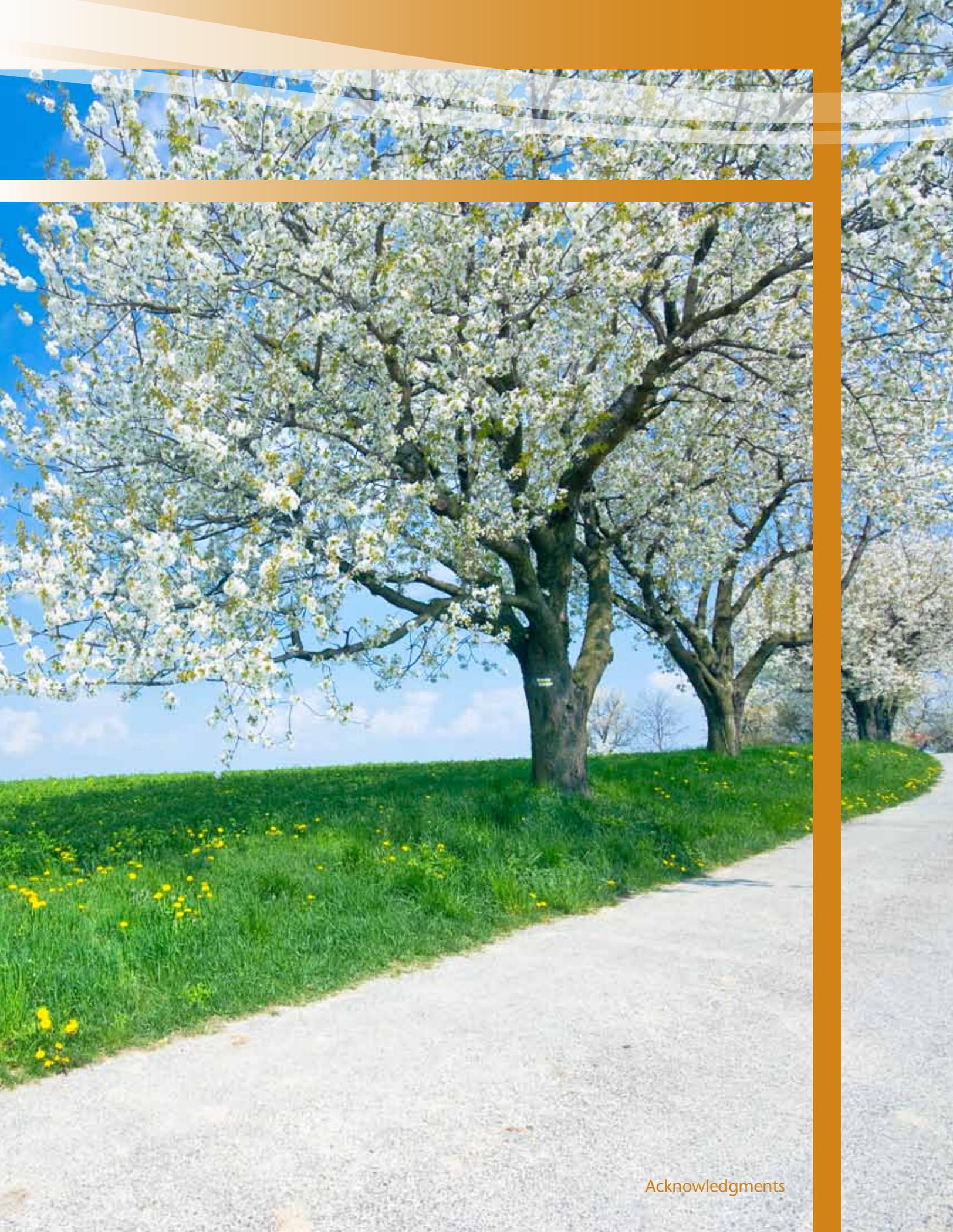




# Table of Contents

Welcome .....	1
TBI Family Caregiver Advisory Panel.....	5
Acknowledgments .....	7
Introduction to the Caregiver’s Guide .....	9
Index to the Guide .....	13

*An electronic version of this Guide can be found at the following Web address:  
[www.traumaticbraininjuryatoz.org](http://www.traumaticbraininjuryatoz.org)*



# Welcome

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*“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

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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.

A handwritten signature in black ink that reads "Michael S. Jaffee". The signature is written in a cursive, flowing style.

**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.



Anne M. Moessner, MSN, RN  
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# Acknowledgments

The Defense and Veterans Brain Injury Center (DVBIC) and the TBI Family Caregiver Advisory Panel wish to acknowledge the contributions of caregivers around the country whose experience informed the development of these modules. In particular, we thank the following individuals who shared their stories for publication:

- 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.
- Meredith H., Marine Corps wife, whose husband Mike was injured while training with his squadron.
- Patty H., Army wife, whose husband Pat was shot in the head while on a night mission in Iraq.
- Meaghan L., Army wife, whose husband Dave sustained a brain injury during a mortar attack in Iraq.
- 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.
- Caroline M., Army Reserve wife, whose husband Patt was injured in Afghanistan when a cell phone-detonated car bomb exploded under the bumper of his vehicle.
- Sandy M., Army wife, whose husband Jason was shot by a sniper while on a mission in Iraq.
- Cindy P., Army parent, whose son Shane was hit by an explosively-formed projectile (EFP) while driving a Humvee in Iraq.
- Emily S., Army wife, whose husband Josh was driving a Humvee in Iraq that was hit by two EFPs.

- Kristen S., Marine Corps wife, whose husband Egbert was a turret gunner in a vehicle blown up by an IED.
- Aimee W., Army wife, whose husband Anthony suffered a penetrating head injury while on duty in Iraq.

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](http://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](http://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).

## A

- Absence Seizures** - Companion, page 2
- Abstract Thinking** - Companion, page 2
- Acceleration** - Companion, page 2
- Acute Care** - Module 2, page 3
- Advanced Medical Directive** - Module 3, page 87 *See living will*
- Advocate** - Module 3, pages 9-15; Module 4, page 7
- Advocacy** - Module 3, pages 9-15; Module 4, pages 7, 101, 105
- Agitated State (Rancho Level IV)** - Module 1, page 33
- Air Force Wounded Warrior (AFW2) Program** - Module 4, page 20
- Alcohol and/or Drug Use** - Module 3, pages 24, 74-76
- Amnesia** - Companion, page 2
- Angiogram** - Companion, page 2
- Anorexia** - Companion, page 2
- Anosmia** - Companion, page 2
- Anoxic Brain Injury** - Companion, page 2
- Anxiety** - Module 2, pages 2, 48, 65, 75, 78; Module 3, pages 19, 23
- Aphasia (Expressive)** - Companion, page 5
- Aphasia (Receptive)** - Companion, page 8
- Appetite Loss (Anorexia)** - Companion, page 2; Module 2, page 26
- Apraxia** - Companion, page 2; Module 2, pages 28-29
- Army Wounded Warrior Program (AW2)** - Module 4, pages 20, 125
- Arthralgia** - Companion, page 2

**Assistive Devices** - Module 3, pages 51, 53, 73

**Ataxia** - Companion, page 2

**Attention Problems** - Module 2, page 38

**Audiologist** - Module 2, page 8

**Avoiding Future TBIs** - Module 3, page 77

**Axons** - Companion, page 2

## **B**

**Balance Problems** - Module 2, page 20

**Balancing Work and Caregiving** - Module 3, page 84

**Basal Ganglia** - Companion, page 2

**Basic Allowance for Subsistence (BAS)** - Module 4, page 78

**Bedsores** - Module 1, page 26

**Behavioral Effects of TBI** - Module 2, pages 65-75

**Frustration, Increased Anger/Aggressiveness** - pages 66-68, 75

**Impulsivity or Difficulties in Self-Control** - page 68

**Poor Judgment** - pages 53, 65, 69

**Reduced or Lack of Initiation** - pages 70, 75

**Repetitive Behaviors (Perseveration)** - pages 60-61, 65, 71

**Less Effective Social Skills** - pages 53, 65, 71

**Changes in Sexual Behaviors** - pages 65, 72

**Lack of Self-Awareness** - pages 53, 65, 73

**Bladder Changes** - Module 2, pages 13, 24

**Blast Injuries** - Companion, page 2; Module 2, page 1

**Bleeding** - Module 1, pages 15-16

**Blood Clots** - Module 1, pages 21-22, 26

**Bowel Changes** - Module 2, pages 13, 24

**Brain** - Companion, page 3

**Brain Anatomy** - Module 1, pages 6-11

**Brain Infection** - Module 1, page 26

**Brain Lobes** - Module 1, pages 8-11  
**Brain Plasticity** - Module 1, page 27  
**Brainstem** - Companion, page 3; Module 1, pages 10-11  
**Bruising** - Module 1, pages 4, 14, 17  
**Burr Hole** - Module 1, page 22

## C

**Caregiver** - Module 1, page 29; Module 3, page 1  
    **Advocacy** - Module 3, pages 9-15; Module 4, pages 7, 101, 105  
    **Burnout** - Module 3, page 19  
    **Challenges** - Module 3, pages 22-23, 41, 60, 93  
    **Definition** - Module 3, page 1  
    **Self-Assessment** - Module 3, pages 28-29  
    **Strategies for Self-Care** - Module 3, page 26  
    **Importance of Caregiving** - Module 3, page 1  
    **Importance of Taking Care of Yourself** - Module 3, pages 17-26  
    **Support Resources** - Module 4, pages 135-137  
**Caregiver and Family Support Resources** - Module 4, pages 135-137  
**Caregiver Support Worksheet**  
    - Companion, pages 23-24; Module 3, pages 66-67  
**Caregiving**  
    **Alternatives** - Module 3, page 45  
    **Finding Meaning in** - Module 3, pages 93-94  
**Case Management** - Module 2, pages 5-6  
**Case Manager/Care Coordinator**  
    - Module 2, pages 6, 8; Module 4, pages 2-3  
**Cerebellum** - Companion, page 3  
**Cerebral Hemispheres** - Module 1, page 7  
**Cerebral Hypoxia** - Companion, page 3  
**Cerebrospinal Fluid (CSF)**  
    - Companion, page 3; Module 1, pages 6, 15, 22, 25

**Cerebrum** - Companion, page 3; Module 1, pages 6, 8, 11

**CHAMPVA** - Module 4, page 36 *See Civilian Health and Medical Program of the Department of Veterans Affairs*

**Chaplain** - Module 2, page 8

**Children and TBI**

- Communicating with Children about TBI** - Module 3, pages 34-35
- Helping Children Cope** - Module 3, pages 31-33, page 36
- Building Family Ties** - Module 3, pages 37-38

**Chronic Subdural Hematoma** - Companion, page 3

**Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)** - Module 4, page 36 *See CHAMPVA*

**Closed Head Injury** - Companion, page 3; Module 1, pages 13-14, 19

**Cognition** - Module 2, page 35

**Coma** - Companion, page 3; Module 1, pages 17, 19, 28, 30-31

**Combat-Related Special Compensation (CRSC)** - Module 4, pages 80, 84

**Combat Zone Injuries – Active Duty Pay Issues** - Module 4, pages 81-83

**Communication Effects of TBI** - Module 2, pages 2, 11, 53-61

- Does Not Speak Clearly** - page 54
- Problems Starting a Conversation** - page 55
- Word Finding Problems** - page 56
- Problems Following a Conversation** - page 56
- Reading Comprehension Problems** - page 57
- Dysarthria** - page 59
- Interrupting or Having a Hard Time Taking Turns in Conversation** - page 59
- Topic Selection Problems** - page 60
- Writing Problems** - page 61
- Nonverbal Communication Issues** - page 61

**Community-Based Managed Care** - Module 4, pages 14-15

- TRICARE: Health Net Federal Services (North Region)**
- TRICARE: Humana Military Healthcare Services (South Region)**

**TRICARE: TriWest Healthcare Alliance (West Region)**

**Community-Based Warrior Transition Unit (CBWTU) –  
Army National Guard or Army Reserve**

**Community-Based Warrior Transition Unit (CBWTU) (Army National Guard or Army Reserve)** - Module 4, pages 15-16

**Complications** - Module 1, pages 25-26

**Compassion Fatigue** - Module 3, page 19

**Compensation Strategies** - Module 2, page 44

**Computed Tomography (CT) (formerly Computerized Axial Tomography [CAT])** - Companion, page 3; Module 1, pages 4, 20

**Concurrent Retirement and Disability Payments (CRDP)**  
- Module 4, page 84

**Concussion (mTBI)** - Companion, page 4; Module 1, pages 3, 14  
*See mild traumatic brain injury*

**Confabulation** - Module 1, page 37; Module 2, page 43

**Confused State (Rancho Levels V and VI)** - Module 1, page 35

**Confusion**  
- Module 1, pages 4, 19, 31, 33-35; Module 2, pages 2, 17, 27, 36-37, 53

**Consciousness** - Companion, page 4

**Continued Health Care Benefit Program (CHCBP)**  
- Module 4, pages 30, 150

**Contusion** - Companion, page 4; Module 1, pages 14, 17

**Conversation Problems** - Module 2, pages 55-60

**Coordination of Movement (Decreased)** - Module 2, pages 13, 28-29

**Counseling/Behavioral Health Options** - Module 4, pages 39-44

**Coup-Contrecoup** - Companion, page 4; Module 1, page 13

**Craniectomy** - Module 1, page 22

**Cranioplasty** - Module 1, page 22

**Craniotomy** - Module 1, page 22

**Cranium (Skull)** - Companion, page 4

**Cueing** - Module 1, page 36; Module 2, pages 45-46

## **D**

- DES (Disability Evaluation System)** - Module 4, pages 99-111
- Deceleration** - Companion, page 4
- Decision Making and Problem Solving** - Module 2, pages 42-43, 69, 76
- Department of Defense (DoD) System of Care** - Module 2, page 4
- Depression** - Module 2, pages 2, 26, 65, 74-76, 78, 80 ; Module 3, page 22
- Diagnostic Tests** - Module 1, page 20
- Dietitian** - Module 2, page 8
- Difficulty with**
- Attention Problems** - Module 2, pages 35, 38-39, 53, 56
  - Conversation** - Module 2, pages 55-56, 59-60
  - Decision Making and Problem Solving**
    - Module 2, pages 42-43, 69, 76
  - Expressing Oneself** - Module 2, pages 53-57
  - Frustration, Increased Anger/Aggressiveness**
    - Module 2, pages 66-68, 75
  - Impulsivity or Self-Control** - Module 2, page 68
  - Initiation** - Module 2, pages 70, 75
  - Memory**
    - Module 2, pages 2, 24, 26, 35-36, 38-40, 42-44, 47, 53, 71
  - Nonverbal Communication** - Module 2, page 61
  - Organization and Planning** - Module 2, pages 40-42
  - Problem Solving** - Module 2, pages 36, 42-43, 48-49
  - Reading Comprehension** - Module 2, page 57
  - Repetitive Behaviors (Perseveration)** - Module 2, pages 65, 71
  - Self-Awareness** - Module 2, pages 53, 65, 73
  - Sexual Behaviors** - Module 2, pages 65, 72-73
  - Social Skills** - Module 2, pages 53, 65, 71
  - Speaking** - Module 2, pages 54, 59, 70
  - Thinking Quickly** - Module 2, page 36
  - Understanding the Spoken Word** - Module 2, pages 53, 56

**Word Finding** - Module 2, page 56

**Writing** - Module 2, page 61

**Diffuse Axonal Injury (DAI)** - Companion, page 4; Module 1, page 17

**Diffuse Brain Injury** - Companion, page 4

**Diplopia (Double Vision)** - Companion, page 4; Module 2, page 21

**Disability**

- Concurrent Retirement and Disability Payments (CRDP)**
  - Module 4, page 84
- Disability Evaluation System (DES)** - Module 4, pages 99-111
- Military Disability System** - Module 4, page 106
- Permanent Disability Retired List (PDRL)**
  - Module 4, pages 18, 78-80, 109
- Temporary Disability Retirement List (TDRL)**
  - Module 4, pages 18, 78-79, 106, 110
- VA Disability System** - Module 4, pages 106, 111
- VA Schedule for Rating Disabilities (VASRD)**
  - Module 4, pages 105-107, 111, 141

**Disability Evaluation System (DES)** - Module 4, pages 99-101, 111, 140, 143

**Disabled Transition Assistance Program (DTAP)** - Module 4, pages 115-116

**Discharge with Severance Pay** - Module 4, pages 78, 84

**Dizziness** - Module 2, pages 18-20

**Double Vision (Diplopia)** - Companion, page 4; Module 2, page 21

**Driving a Vehicle** - Module 3, pages 72-74

**Dura** - Module 1, pages 6, 15-16, 26

**Dura Mater** - Companion, page 4; Module 1, page 6

**Dysarthria** - Companion, page 4; Module 2, page 59

**Dyskinesia** - Companion, page 4

## **E**

**Edema** - Module 1, page 25

**Electroencephalograph, or EEG** - Companion, page 4; Module 1, page 20

- Eligibility Status** - Module 4, pages 10, 33
- Emergence from Coma (Rancho Levels II and III)** - Module 1, page 30
- Emergency Help** - Module 4, page 92
- Emotional Effects of TBI** - Module 2, pages 74-80
- Depression** - pages 2, 26, 65, 74-76, 78 ,80
  - Increased Anxiety** - page 78
  - Mood Swings** - page 79
  - Changes in Self-Esteem** - page 80
- Educational Assistance**
- Education Benefits for Family Members** - Module 4, page 67
  - Education Benefits for Caregivers** - Module 4, page 67
  - Education Benefits for Service Members and Veterans**  
- Module 4, pages 57-65, 157-158
  - Survivors' and Dependents' Educational Assistance**  
- Module 4, page 66
  - Vocation and Education Counseling for Veterans**  
- Module 4, page 66
- Employment Assistance**
- Employment Benefits for Caregivers** - Module 3, pages 82-84  
*See job benefits*
  - Employment Opportunities for Service Members/Veterans**  
- Module 4, pages 53-54 *See job opportunities for service members/veterans*
  - Employment-Related Services** - Module 4, pages 49-52  
*See job-related services*
  - Employment Resources for Caregivers** - Module 4, page 55  
*See job resources for caregivers*
- Endotracheal Tube** - Module 1, page 23
- Epidural Hematoma** - Companion, page 4; Module 1, page 16
- Estate Planning** - Module 3, page 87 *See trust*
- Euphoria** - Companion, page 4
- Executive Functions** - Companion, page 5

**Expressive Aphasia** - Companion, page 5

**Eyeballs, rapid movement (nystagmus)** - Companion, page 7

## **F**

**Family Assistance Centers** - Module 4, page 19

**Family and Medical Leave Act (FMLA)** - Module 3, page 81

**Family Strengths** - Module 3, pages 41-42

**Family Ties** - Module 3, pages 37-38

### **Fatigue**

- Module 1, pages 4, 32, 34; Module 2, pages 2, 13-14, 17-18, 39, 66, 75

**Federal Recovery Coordinator (FRC)** - Module 4, page 5

**Feedback** - Module 2, pages 44, 47, 54, 62

**Fever** - Module 1, page 25

**Fisher Houses** - Module 4, page 71

**Fluid Restriction** - Module 1, pages 21, 25

**Focal Brain Injury** - Companion, page 5

**Fracture** - Module 1, pages 2, 15, 22, 26

**Frontal Lobe** - Companion, page 5; Module 1, pages 8-9

**Frustration, Increased Anger/Aggressiveness** - Module 2, pages 66-68, 75

## **G**

### **GI Bill**

**Post-9/11 GI Bill** - Module 4, pages 57-58

**Montgomery GI Bill – Active Duty (MGIB)**

- Module 4, pages 60-62

**Montgomery GI Bill – Selected Reserve (MGIB-SR)**

- Module 4, pages 59-60

**Generalized Tonic-Clonic Seizures** - Companion, page 5

### **Glasgow Coma Scale (GCS)**

- Companion, page 5; Module 1, pages 4, 19, 43

**Guardianship** - Module 3, pages 5, 85

## H

- Headache** - Module 2, pages 8, 14-17, 76
- Health Care Providers** - Module 1, pages 19, 36-37; Module 2, pages 1, 8-10, 24-25
- Health Care Team Member Information Form**  
- Companion, pages 18-20; Module 3, pages 64-65
- Hematoma** - Companion, page 5; Module 1, pages 6, 14-16
- Hemiparesis** - Module 2, page 23
- Hemiplegia** - Module 2, page 23
- Hemorrhage** - Module 1, pages 6, 14-16
- Herniation/Herniated** - Companion, page 5
- Heterotrophic Ossification** - Module 2, page 32
- High Functional Level (Rancho Levels VII and VIII)** - Module 1, page 38
- Home Care Team** - Module 3, pages 54-59
- Home Care Team Volunteer Form**  
- Companion, page 25; Module 3, page 63
- Home Health Care** - Module 3, page 62
- Home Loan Program (VA)** - Module 4, page 74
- Home Modification** - Module 3, page 54; Module 4, page 72
- Home Safety** - Module 3, pages 72, 77
- Home Safety Checklist** - Module 3, pages 78-79
- Homes for Our Troops** - Module 4, page 73
- Housing Benefits** - Module 4, pages 71-76
- Housing (Temporary) for Caregivers** - Module 4, page 71  
Malone House  
Navy Lodges  
Fisher Houses
- Hydrocephalus** - Module 1, page 25
- Hypothalamus** - Module 1, page 10
- Hypoxia** - Companion, page 5

**I**

**Impaired Initiation** - Companion, page 5

**Improvised Explosive Devices, or IEDs** - Companion, page 5

**Impulsivity or Difficulties in Self-Control** - Module 2, page 68

**Initiation (Reduced or Lack of)** - Module 2, pages 70, 75

**Inpatient Care/Treatment** - Module 2, pages 3, 5-6, 44; Module 4, page 14

**Insurance Assistance**

- Insurance for Veterans** - Module 4, pages 90-91
- Traumatic Servicemembers' Group Life Insurance (TSGLI)**
  - Module 4, page 85

**Intensive Care Unit (ICU)** - Module 1, page 31

**Intimacy** - Module 3, page 43

**Intracerebral Hemorrhage** - Companion, page 6

**Intracranial Pressure, or ICP**

- Companion, page 6; Module 1, pages 20, 25

**Intracranial Pressure (ICP) Monitor** - Companion, page 6

**Intravenous Tubes (IVs)** - Module 1, page 23

**Intraventricular Hemorrhage** - Module 1, page 16

**J**

**Job Assistance**

- Job Benefits for Caregivers** - Module 3, pages 82-84
  - See employment benefits for caregivers*
- Job-Related Services** - Module 4, pages 49-52
  - See employment-related services*
- Job Opportunities for Service Members/Veterans**
  - Module 4, pages 53-54 *See employment opportunities for service members/veterans*
- Job Resources for Caregivers** - Module 4, page 55
  - See employment resources for caregivers*

**Joint Pain, Stiffness (Arthralgia)** - Companion, page 2

**Judgment (Poor)** - Module 2, pages 53, 65, 69

## L

- Legal Services** - Module 4, page 93
- Limbic System** - Companion, page 6; Module 1, page 10
- Living Will** - Module 3, pages 85, 87 *See advanced medical directive*
- Lobe** - Companion, page 6
- Lobes of the Brain** - Module 1, pages 8-10
- Low Blood Pressure** - Module 1, page 25

## M

- MEB (Medical Evaluation Board)** - Module 4, pages 101-104
- Magnetic Resonance Imaging, or MRI**
  - Companion, page 6; Module 1, page 20
- Malone House** - Module 4, page 71
- Marine Corps Wounded Warrior Regiment (WWR)**
  - Module 4, pages 23-24, 126
- Marriage or Relationship Issues** - Module 3, pages 43-44
- Medical Evaluation Board (MEB)** - Module 4, pages 101-104
- Medical Evaluation Board (MEB) Resources** - Module 4, pages 139-141
- Medical Power of Attorney** - Module 3, page 87
- Medical Retirement** - Module 4, page 17
  - Disability Payments** - Module 4, page 84
- Medication Log** - Companion, pages 21-22; Module 3, page 7
- Medication Management** - Module 3, pages 52-53
- Memory**
  - Memory Difficulty** - Module 2, pages 2, 24, 26-27, 36, 39, 43, 53
  - Memory Compensation**
    - Module 2, pages 18, 29, 38-40, 42, 44, 47, 71, 74
- Meninges** - Companion, page 6; Module 1, page 6
- Mild Traumatic Brain Injury, or mTBI**
  - Companion, page 6; Module 1, pages 3-4 *See concussion*
- mTBI (Mild Traumatic Brain Injury)**
  - Companion, page 6; Module 1, pages 3-4 *See concussion*

**Military Acute Concussion Evaluation, or MACE** - Companion, page 6

**Military Disability System** - Module 4, page 106

**Military Liaison (Department of Defense)** - Module 2, page 6, 8

**Military Medical Centers** - Module 2, page 89

**Military Terms Related to Injuries and Treatment**

- Companion, page 14

**BI** – Battlefield Injury

**CASEVAC** – Casualty Evacuation

**MTF** – Medical Treatment Facility; for example:

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

**NMCS D** – 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

**Military Terms (Other) - Companion, page 15**

**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

**Military Ranks** - Companion, pages 10-13  
**Military Treatment Facility (MTF)** - Module 2, page 3  
**Minimally Conscious State** - Module 1, page 30  
**Moderate to Severe TBI** - Module 1, pages 4, 27-28  
**Montgomery GI Bill – Active Duty (MGIB)** - Module 4, pages 60-62  
**Montgomery GI Bill – Selected Reserve (MGIB-SR)**  
- Module 4, pages 59-60  
**Mood Swings** - Module 2, page 79  
**Movement, Involuntary (Dyskinesia)** - Module 2, page 30  
**Muscle Pain (Myalgia)** - Companion, page 6  
**My Healthvet – VA Personal Health Record** - Module 4, page 36  
**Myalgia** - Companion, page 6

## **N**

**Nasogastric Tube (NG tube)** - Module 1, page 23  
**National Resource Directory** - Module 4, page 71  
**Navy Lodges** - Module 4, page 71  
**Navy Safe Harbor Program** - Module 4, pages 22-23  
**Neurochemistry** - Module 1, pages 1, 18  
**Neurocognitive** - Companion, page 6  
**Neurological Exam** - Module 1, page 19  
**Neurologist** - Module 2, page 8  
**Neuron** - Companion, page 7  
**Neuro-ophthalmologist** - Module 2, page 9  
**Neuropsychological Evaluation** - Module 2, page 35  
**Neuropsychologist** - Module 2, pages 9, 35  
**Neuropsychology** - Companion, page 7  
**Neuroradiological Tests** - Companion, page 7  
**Neurosurgeon** - Module 1, page 15; Module 2, page 9  
**Neurotransmitters** - Companion, page 7; Module 1, page 18

**Nonverbal Communication Issues** - Module 2, page 61

**Nystagmus** - Companion, page 7

## **O**

**Occipital Lobe** - Companion, page 7; Module 1, pages 8, 10-11

**Occupational Therapist (OT)** - Module 2, pages 9, 23, 25, 36, 44

**Ocular** - Companion, page 7

**Open Head Injury** - Companion, page 7

**Operation IMPACT** - Module 4, page 55

**Organization and Planning Problems** - Module 2, pages 40-42

**Organization Needs of Caregivers**

**Organizing Medical Records** - Module 3, pages 3-5

**Organizing Military Records** - Module 3, pages 3-5

**Outpatient Care/Treatment** - Module 2, page 3; Module 4, page 14

## **P**

**Pay, Types of**

**For Active Duty Service Members** - Module 4, pages 77-78

**Specific to Combat Zone Injuries** - Module 4, pages 81-83

**For Medically Retired** - Module 4, pages 78-84

**PEB (Physical Evaluation Board)** - Module 4, pages 78,104-105, 108, 109

**PEB Resources** - Module 4, pages 143-148

**Right to Appeal PEB Decision** - Module 4, pages 139-141

**PEG Tube (Per Cutaneous Gastronomy Tube)** - Module 1, page 23

**PRC (VA Polytrauma Rehabilitation Centers)** - Module 2, pages 5, 6, 7

**Parietal Lobe** - Companion, page 7, Module 1, page 9

**Penetrating Head Injury** - Companion, page 7; Module 1, page 13

**Per Cutaneous Gastronomy Tube (PEG tube)** - Module 1, page 23

**Peripheral Fatigue** - Module 2, page 17

**Permanent Disability Retired List (PDRL)** - Module 4, pages 80, 109

**Perseveration** - Companion, page 7; Module 2, pages 60-61, 65, 71

**Photophobia** - Companion, page 7

**Physiatrist** - Module 2, page 9

**Physical Evaluation Board (PEB)** - Module 4, pages 78,104-105, 108, 109

**Physical Therapist (PT)** - Module 2, pages 10, 18, 20, 22-23

**Pneumonia** - Module 1, pages 25-26, 32

**Point of Contact (POC)** - Module 3, page 49; Module 4, pages 1-6  
*See Case Manager/Care Coordinator, Federal Recovery Coordinator, Recovery Care Coordinator, VA Liaison, Military Liaison*

**Polytrauma** - Module 2, pages 3-7, 89

**Positron Emission Tomography, or PET Scan** - Companion, page 7

**Post-9/11 GI Bill** - Module 4, pages 57-58

**Post-Deployment Health Assessment, or PDHA** - Companion, page 8

**Post-Deployment Health Reassessment, or PDHRA** - Companion, page 8

**Post-Traumatic Amnesia (PTA)**  
- Companion, page 8; Module 1, pages 19, 31, 34

**Post-Traumatic Stress (PTS)**  
- Companion, page 8; Module 2, page 2; Module 4, pages 41-42

**Post-Traumatic Stress Disorder (PTSD)** - Module 2, page 2

**Power of Attorney (POA)** - Module 3, pages 85-87

**Primary Care Provider** - Module 2, page 10

**Problem Solving** - Module 2, pages 36, 42-43, 48-49

**Pulmonary Embolus (PE)** - Module 1, page 26

## **R**

### **Rancho Los Amigos Levels of Cognitive Functioning**

- Companion, page 8; Module 1, pages 29, 45-51

#### **Emergence from Coma (Rancho Levels II and III)**

- Module 1, page 30

**Agitated State (Rancho Level IV)** - Module 1, page 33

**Confused State (Rancho Levels V and VI)** - Module 1, page 35

**High Functional Level (Rancho Levels VII and VIII)**

- Module 1, page 38

**Reading Comprehension Problems** - Module 2, page 57

**Receptive Aphasia** - Companion, page 8

**Recovery**

**Course of** - Module 1, page 2; Module 3, page 1

**Process** - Module 1, pages 3, 25, 27-29

**Stages of** - Module 1, pages 29-39

**Recovery Care Coordinator (RCC)** - Module 4, page 6

**Recreational Therapist (RT)** - Module 2, page 10

**Rehabilitation** - Module 1, page 2, 28; Module 3, page 3

**Rehabilitation Nurse** - Module 2, page 10

**Rehabilitation Psychologist** - Module 2, page 10

**Rehabilitation Medical Support Resources** - Module 4, pages 149-155

**Repetitive Behaviors (Perseveration)** - Module 2, pages 60-61, 65, 71

**Residential Care** - Module 3, pages 45-46

**Respite Care** - Module 3, pages 60-62

**ringing in the Ears (Tinnitus)** - Companion, page 9; Module 2, pages 8, 21

## **S**

**Safety** - Module 3, pages 72, 77 *See Home Safety*

**Seizure** - Companion, page 8; Module 2, pages 29-31

**Self-Awareness (Lack of)** - Module 2, pages 53, 65, 73

**Self-Esteem** - Module 2, pages 65, 80

**Sensitivity to Light (Photophobia)**

- Companion, page 7; Module 2, pages 15, 21

**Sensory Changes** - Module 2, page 21

**Sexuality** - Module 2, pages 65, 72; Module 3, pages 43-44

**Single-Photon Emission Computed Tomography, or SPECT Scan**

- Companion, page 9

**Skin Breakdown** - Module 1, page 26

**Skull** - Module 1, pages 6, 9, 13-16, 20, 22, 25, 27

**Skull Fracture** - Companion, page 9; Module 1, pages 14-15, 22, 26

- Simple Fracture** - Module 1, page 15
- Compound Fracture** - Module 1, page 15
- Depressed Skull Fracture** - Module 1, page 15
- Basal Skull Fracture** - Module 1, page 15

**Sleep Changes** - Module 2, pages 2, 15-16, 75

**Slowed Speed of Processing** - Module 2, page 37

**Smell, Loss or Decrease (Anosmia)**  
- Companion, page 2; Module 2, pages 13, 21-22, 26, 30

**Social Skills (Less Effective)** - Module 2, pages 53, 65, 71

**Social Worker** - Module 2, pages 8, 10

**Social Security Benefits** - Module 4, page 88

**Spasticity** - Module 2, pages 13, 22-23

**Speech Problems** - Module 2, pages 18, 53-54, 59

**Speech Language Pathologist (SLP)** - Module 2, page 10

**State Benefits** - Module 4, pages 117-123

**Stimulation Techniques** - Module 1, page 31

**Stress** - Module 3, pages 22, 26-27

**Subarachnoid Hemorrhage** - Module 1, pages 6, 16

**Subdural Hematoma** - Companion, page 9; Module 1, pages 6, 16

**Suicide Prevention** - Module 4, pages 42-43

**Support Programs, Air Force** - Module 4, pages 19-20

- Patient Squadron Program**
- Reserve Component Airmen**
- Air Force Wounded Warrior (AFW2) Program**
- Assistance for Air Force Families**

**Support Programs, Army** - Module 4, pages 20-22

- Army Wounded Warrior Program (AW2)**

**Warrior Transition Unit (WTU)**  
**Community-Based Warrior Transition Unit (CBWTU)**  
**Assistance for Army Families**  
**Support Programs, Marine Corps - Module 4, pages 23-24**  
**Marine Corps Wounded Warrior Regiment (WWR)**  
**Assistance for Marine Families**  
**Support Programs, Navy - Module 4, pages 22-23**  
**Navy Safe Harbor Program**  
**Assistance for Navy Families**  
**Surgery, Types of - Module 1, page 22**  
**Survivors' and Dependents' Educational Assistance - Module 4, page 66**  
**Swallowing Changes - Module 2, pages 13, 25**  
**Swelling (Edema) - Module 1, page 25**

## **T**

**TBI Classification - Module 1, pages 3-4**  
**TBI Definition - Companion, page 9; Module 2, page 2**  
**TBI Continuum of Care - Module 4, page 13**  
**Inpatient Medical Care (Continental U.S.)**  
**DoD Military Treatment Facility (MTF)**  
- Module 2, pages 4, 89  
**VA Polytrauma System of Care (PSC)**  
- Module 2, page 5; Module 4, page 5  
**Outpatient Rehabilitation**  
**DoD Military Treatment Facility (MTF)**  
- Module 2, pages 4, 89  
**VA Polytrauma System of Care (PSC)**  
- Module 2, page 5; Module 4, page 5  
**VA Polytrauma Network Sites (PNS) - Module 2, page 5**  
**VA Polytrauma Rehabilitation Centers (PRC)**  
- Module 2, pages 5, 6, 89

**TRICARE Network Community-based Managed Care**

- Module 4, pages 14,15

**TBI Model Systems Centers** - Module 2, pages 90-92

**TBI Prevalence** - Module 1, page 3

**TBI Types** - Module 1, pages 13-14

**TSGLI (Traumatic Servicemembers' Group Life Insurance)**

- Module 4, page 85

**Temporal Lobe** - Companion, page 9; Module 1, pages 8-9

**Temporary Disability Retirement List (TRDL)** - Module 4, pages 79, 110

**Thalamus** - Companion, page 9; Module 1, pages 10-11

**Thinking Skills**

**Confusion** - Module 2, page 36

**Slowed Speed of Processing** - Module 2, page 37

**Attention Problems** - Module 2, pages 35, 38-39, 53, 56

**Memory Difficulty**

- Module 2, pages 2, 24, 26, 35-36, 38-44, 47, 53, 71

**Memory Compensation**

- Module 2, pages 18, 29, 38-44, 47, 71, 74

**Organization and Planning Problems** - Module 2, pages 40-42

**Decision Making and Problem Solving**

- Module 2, pages 42-43, 69, 76

**Confabulation** - Module 1, page 37; Module 2, page 43

**Compensation Strategies** - Module 2, page 44

**Cueing** - Module 1, page 36; Module 2, pages 27, 40, 45-46

**5W Strategy** - Module 2, page 47

**Feedback** - Module 2, pages 47-48, 54, 62

**Problem Solving** - Module 2, pages 36, 42-43, 48-49

**Tinnitus** - Companion, page 9; Module 2, pages 8, 21

**Tracheostomy Tube** - Module 1, page 23

**Transition Assistance Program (TAP)** - Module 4, pages 113-115

**Transitional Assistance Management Program (TAMP)**

- Module 4, page 29

- Transitioning to Home** - Module 3, pages 49-51, 70-71
- Traumatic Brain Injury, or TBI** - Companion, page 9; Module 2, page 2
- Mild Traumatic Brain Injury, or mTBI**
    - Companion, page 6; Module 1, pages 3-4 *See Concussion*
  - Moderate to Severe TBI** - Module 1, pages 4, 16, 27-28
- Traumatic Servicemembers' Group Life Insurance (TSGLI)**
  - Module 4, page 85
- Travel Benefits**
- Travel Benefits for Service Members/Veterans**
    - Module 4, pages 81, 95-96
  - Travel Benefits for Caregivers** - Module 4, pages 82, 97
- Treatment, Phases of** - Module 2, page 3
- TRICARE**
- TRICARE for Life** - Module 4, page 89
  - TRICARE Dental Program (TDP)** - Module 4, page 30
  - TRICARE Military Medical Support Office (MMSO)**
    - Module 4, page 32
  - TRICARE Network Community-Based Managed Care**
    - Module 4, pages 14,15
  - TRICARE Reserve Select (TRS)** - Module 4, page 28
  - TRICARE Retiree Dental Program** - Module 4, page 31
  - TRICARE Services and Benefits** - Module 4, pages 25-27
- Trust** - Module 3, page 88 *See estate planning*
- Tubes, Types of** - Module 1, page 23
- U**
- Unemployment Compensation** - Module 4, page 118
- Urinary Catheter** - Module 1, page 23

## V

**VA Disability System** - Module 4, pages 106, 111

### **VA Health Care System**

**Eligibility, Enrollment, Services** - Module 4, pages 33-35

**Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)** - Module 4, page 36

**VA Personal Health Record – My Healthevet** - Module 4, page 36

**VA Polytrauma Network Sites (PNS)** - Module 2, page 5

**VA Polytrauma Rehabilitation Centers (PRC)**  
- Module 2, pages 5, 6, 89

**VA Polytrauma System of Care (PSC)**  
- Module 2, page 5; Module 4, page 5

**VA Liaison** - Module 4, pages 2,3, 24

**VA Polytrauma Network Sites (PNS)** - Module 2, page 5

**VA Polytrauma Rehabilitation Centers (PRC)** - Module 2, pages 5, 6, 89

**VA Polytrauma System of Care (PSC)**  
- Module 2, pages 5-6; Module 4, page 5

**VA Schedule for Rating Disabilities (VASRD)**  
- Module 4, pages 105-107, 141

**VA State Offices** - Module 4, pages 119-123

**Vegetative State** - Module 1, page 30

**Ventilator** - Module 1, pages 22-23

**Ventricles** - Module 1, pages 6, 16, 22, 25

**Ventricular Drain or Ventriculostomy** - Module 1, page 22

**Veterans Benefits Administration (VBA)** - Module 2, page 6

**Veterans Educational Assistance Program (VEAP)**  
- Module 4, pages 60, 62-63

**Veterans Service Organizations (VSOs)** - Module 4, pages 129-131

**Veterans Upward Bound (VUB) Program** - Module 4, pages 63-64

**Vision Problems** - Module 2, pages 13, 19, 21, 27-28, 54

**Visual Spatial Problems** - Module 2, pages 27-28

**Vocational Rehabilitation and Employment Program (VR&E)**  
- Module 4, page 65

**Vocational Rehabilitation Counselor** - Module 2, page 10

## **W**

**5W Strategy (Who, What, Where, When, Why)** - Module 2, page 47

**Warrior Transition Unit (WTU)** - Module 4, pages 21-22

**Water on the Brain (Hydrocephalus)** - Module 1, page 25

**Web Page/Site, Personalized** - Module 3, page 59

**Weight Loss or Gain** - Module 2, pages 25-26

**Whiplash** - Companion, page 9

**Word Finding Problems** - Module 2, page 56

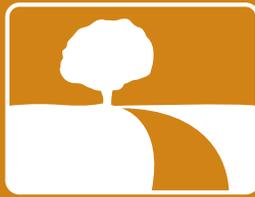
**Writing Problems** - Module 2, page 61



## Notes







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