Defense Health Board Meeting
August 17, 2009

Traumatic Brain Injury Family Caregiver Panel Update

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Lead Agency: Defense and Veterans Brain Injury Center

A Component center of the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury

Presentation Objectives

- Review purpose of the TBI Family Caregiver Panel
- Review curriculum development process
- Describe modules, content, formats, qualitative review, refinement, distribution
- Review timeline
- Outline agenda for final panel meeting (October 14 and 15, 2009)

National Defense Authorization Act of 2007 (NDAA), Section 744

Mandated the establishment of a 15-member panel:

"to develop 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."

National Defense Authorization Act of 2007 (NDAA), Section 744

- Law stipulates that certain categories of individuals must be included on the panel:
  - medical professionals specializing in TBI (combat TBI as well) including psychologists with expertise in the mental health treatment and care of TBI
  - family caregivers and representatives of family caregivers or family caregiver associations
  - DoD & DVA health & medical personnel with expertise in TBI
  - experts in the development of training curricula
  - family members of members of the Armed Forces with TBI

- Panel members were appointed after receiving DoD and White House approval on 06 March 2008

DVBIC Role

- Provide programmatic and logistical support to ensure
  - Development of curriculum according to congressional mandate
  - Content accuracy
  - Implementation and ongoing maintenance of the curriculum

Tasks of the Panel

- Review literature and developing an evidence-base for the curriculum
- Develop consistent curriculum for TBI caregiver education
- Recommend mechanisms for the dissemination of the family caregiver curriculum throughout DoD and VA

Caregiver Definition

"Any family or support person (s) relied upon by the service member or veteran with Traumatic Brain Injury, who assumes primary responsibility for ensuring the needed level of care and overall well-being of that service member or veteran"

*For the purposes of the curriculum, "family" or "family caregiver" will include spouse, parents, children, other extended family members, as well as significant others and friends

Benefits of Curriculum

- Uniform resource for caregivers through:
  - Consistent message
  - Tools for coping and gaining assistance
  - Giving hope while navigating life after TBI
- Curriculum will:
  - Be informative and accurate
  - Provide self management skills
  - Teach skills for communicating with health care and other teams
  - Be user friendly and culturally appropriate
  - Be based on real life needs and experiences

Modules

- Module 1 - Introduction to TBI (learning about the brain, causes and types of TBI, acute care issues, possible complications, recovery process, helpful suggestions)
- Module 2 - Understanding Effects of TBI and What You Can do to Help (physical, cognitive, communication, behavioral, and emotional effects; related practical strategies)

Modules

- Module 3 - Becoming a Family Caregiver for a Service Member/Veteran with TBI (starting the journey, caring for your service member/veteran, caring for yourself, helping children cope, addressing family needs, everyday issues, planning for the future, becoming an advocate, finding meaning in caregiving)

Modules

- Module 4 - Navigating the System (recovery care, eligibility for compensation and benefits, compensations, rehabilitation medical support, entitlements & benefits related to employment and community reintegration)

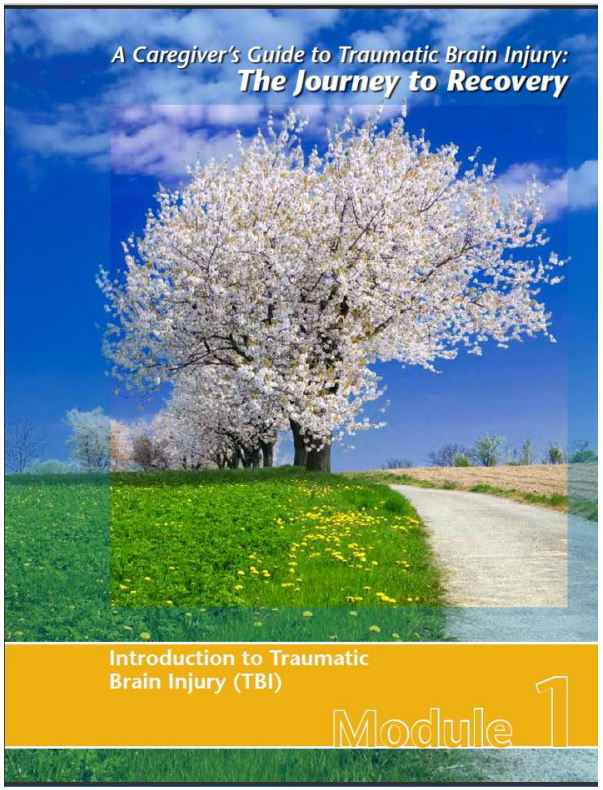
January 2009 Panel Meeting

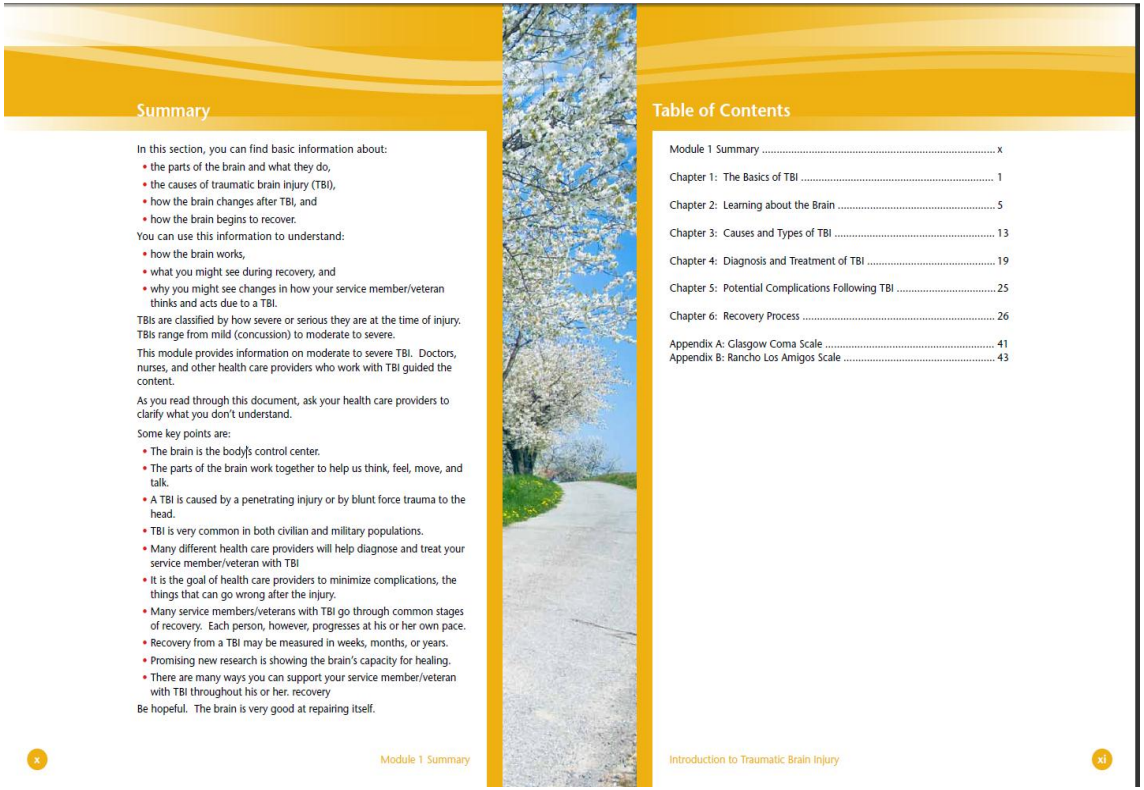
- Final work groups formed for completion of project:
  - Design & Editing
  - Multi-media
  - Qualitative Process Review
  - Dissemination
- Decision made to create a separate Mild TBI Patient Education Guide

Design & Editing Update

- Final module editing including content, vignettes, graphics, layout, and packaging
- Acknowledgments completed
- Consensus for 8th grade reading level
- Workbook (similar to “Keeping it all together”) designed and finalized
- 100 copies printed and packaged for Qualitative Review Process

Design & Editing Update





Summary

In this section, you can find basic information about:

- the parts of the brain and what they do,
- the causes of traumatic brain injury (TBI),
- how the brain changes after TBI, and
- how the brain begins to recover.

You can use this information to understand:

- how the brain works,
- what you might see during recovery, and
- why you might see changes in how your service member/veteran thinks and acts due to a TBI.

TBIs are classified by how severe or serious they are at the time of injury. TBIs range from mild (concussion) to moderate to severe.

This module provides information on moderate to severe TBI. Doctors, nurses, and other health care providers who work with TBI guided the content.

As you read through this document, ask your health care providers to clarify what you don't understand.

Some key points are:

- The brain is the body's control center.
- The parts of the brain work together to help us think, feel, move, and talk.
- A TBI is caused by a penetrating injury or by blunt force trauma to the head.
- TBI is very common in both civilian and military populations.
- Many different health care providers will help diagnose and treat your service member/veteran with TBI
- It is the goal of health care providers to minimize complications, the things that can go wrong after the injury.
- Many service members/veterans with TBI go through common stages of recovery. Each person, however, progresses at his or her own pace.
- Recovery from a TBI may be measured in weeks, months, or years.
- Promising new research is showing the brain's capacity for healing.
- There are many ways you can support your service member/veteran with TBI throughout his or her. recovery

Be hopeful. The brain is very good at repairing itself.

x Module 1 Summary

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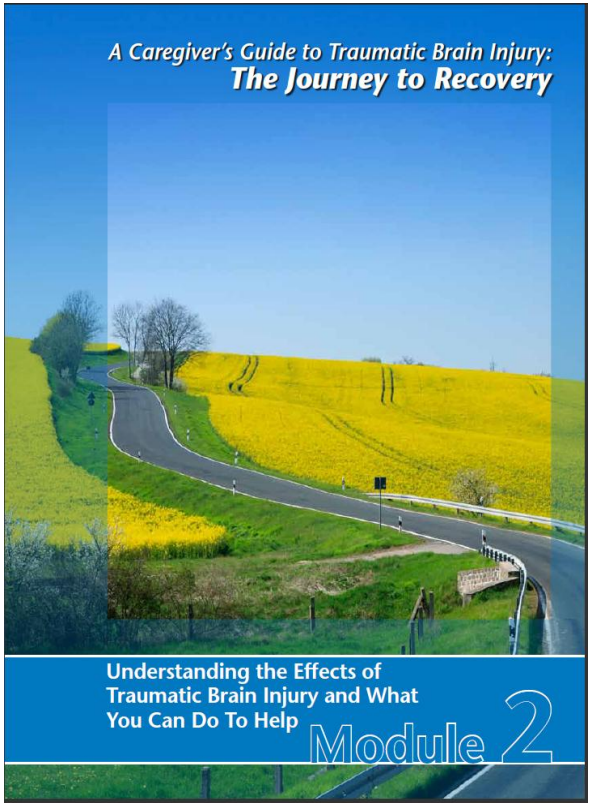
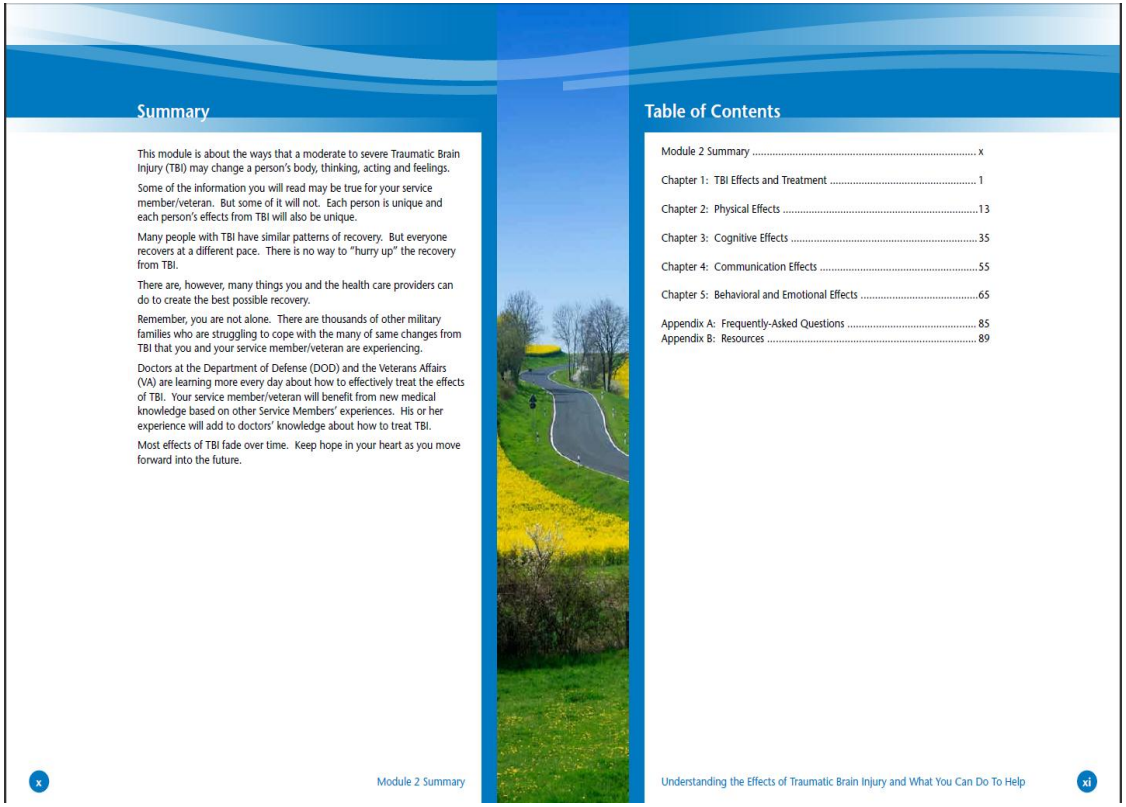
Chapter 4: Diagnosis and Treatment of TBI 19
Chapter 5: Potential Complications Following TBI 25
Chapter 6: Recovery Process 26
Appendix A: Glasgow Coma Scale 41
Appendix B: Rancho Los Amigos Scale 43

Introduction to Traumatic Brain Injury xi

Design & Editing Update





Summary

This module is about the ways that a moderate to severe Traumatic Brain Injury (TBI) may change a person's body, thinking, acting and feelings.

Some of the information you will read may be true for your service member/veteran. But some of it will not. Each person is unique and each person's effects from TBI will also be unique.

Many people with TBI have similar patterns of recovery. But everyone recovers at a different pace. There is no way to "hurry up" the recovery from TBI.

There are, however, many things you and the health care providers can do to create the best possible recovery.

Remember, you are not alone. There are thousands of other military families who are struggling to cope with the many of same changes from TBI that you and your service member/veteran are experiencing.

Doctors at the Department of Defense (DOD) and the Veterans Affairs (VA) are learning more every day about how to effectively treat the effects of TBI. Your service member/veteran will benefit from new medical knowledge based on other Service Members' experiences. His or her experience will add to doctors' knowledge about how to treat TBI.

Most effects of TBI fade over time. Keep hope in your heart as you move forward into the future.

x Module 2 Summary

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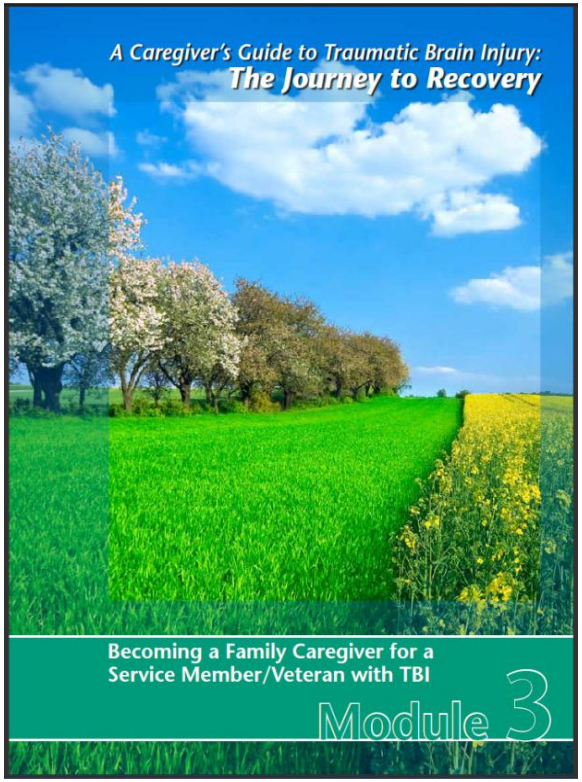
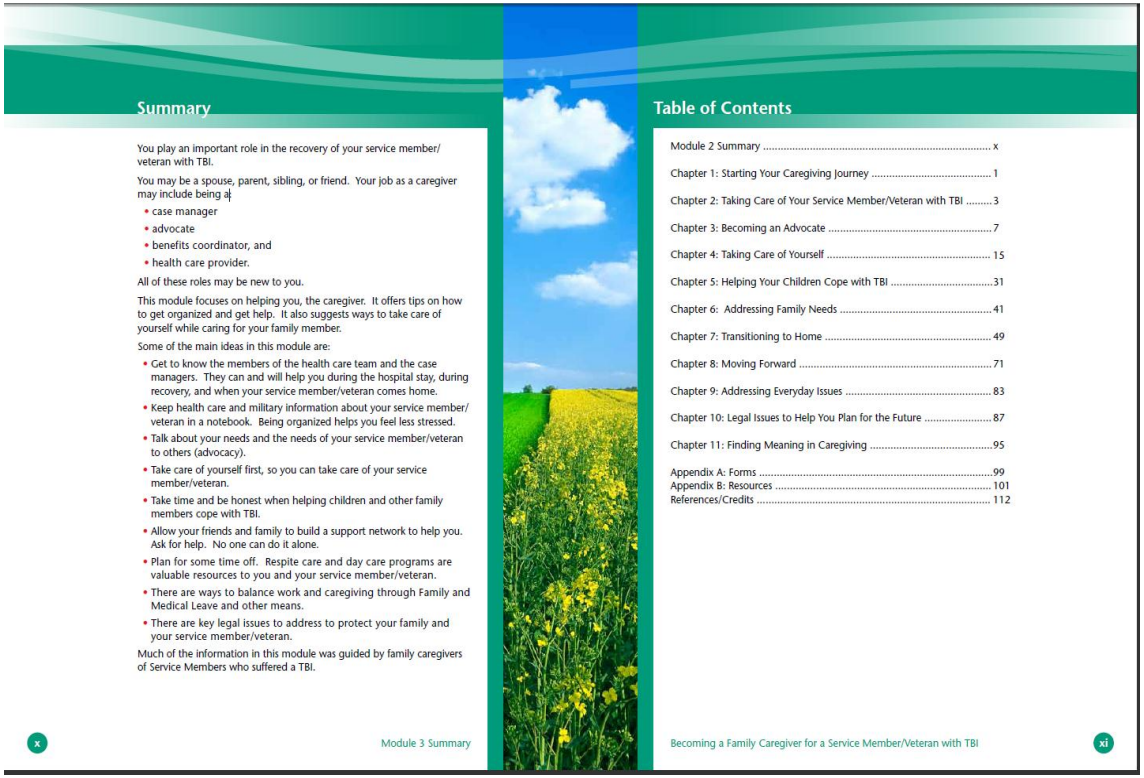
Understanding the Effects of Traumatic Brain Injury and What You Can Do To Help xi

Design & Editing Update





Summary

You play an important role in the recovery of your service member/veteran with TBI.

You may be a spouse, parent, sibling, or friend. Your job as a caregiver may include being a

- case manager
- advocate
- benefits coordinator, and
- health care provider.

All of these roles may be new to you.

This module focuses on helping you, the caregiver. It offers tips on how to get organized and get help. It also suggests ways to take care of yourself while caring for your family member.

Some of the main ideas in this module are:

- Get to know the members of the health care team and the case managers. They can and will help you during the hospital stay, during recovery, and when your service member/veteran comes home.
- Keep health care and military information about your service member/veteran in a notebook. Being organized helps you feel less stressed.
- Talk about your needs and the needs of your service member/veteran to others (advocacy).
- Take care of yourself first, so you can take care of your service member/veteran.
- Take time and be honest when helping children and other family members cope with TBI.
- Allow your friends and family to build a support network to help you. Ask for help. No one can do it alone.
- Plan for some time off. Respite care and day care programs are valuable resources to you and your service member/veteran.
- There are ways to balance work and caregiving through Family and Medical Leave and other means.
- There are key legal issues to address to protect your family and your service member/veteran.

Much of the information in this module was guided by family caregivers of Service Members who suffered a TBI.

x Module 3 Summary

Table of Contents

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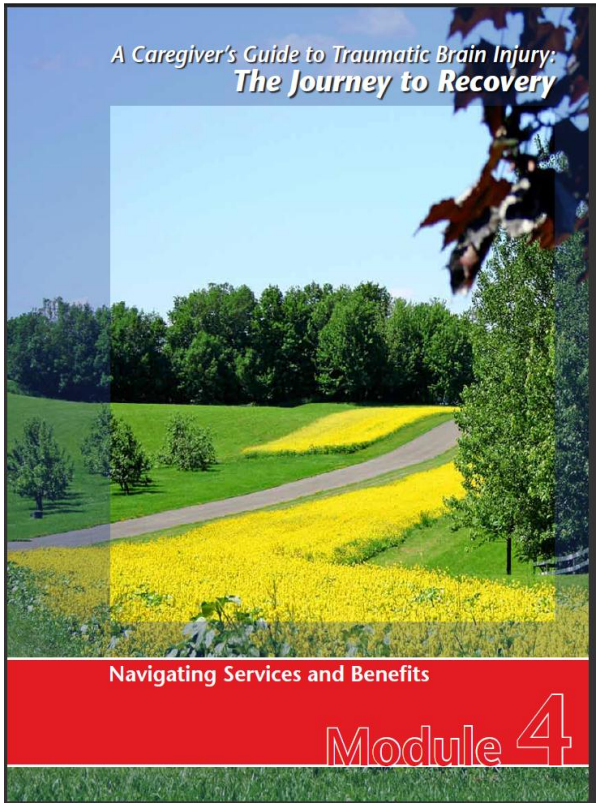
Becoming a Family Caregiver for a Service Member/Veteran with TBI xi

Design & Editing Update



Summary

This module is about benefits and services from the Department of Defense (DoD) and the Department of Veterans' Affairs (VA). Being a member of the military brings both honor and support. You want to be sure your family member gets the support—services and benefits-- that he or she deserves.

It can be hard to find your way through the maze of programs at DoD and the VA. The good news is that you are not alone. There are many caring professionals at both agencies who can guide you. Your family member will also have a Point of Contact (POC). He or she is the first person to turn to for information. (What this person is called depends on your family member's military branch.)

You also have an important role to play on your family member's behalf. **Part of being a caregiver is to be an advocate**, for both your family member and for you. You need to speak up, clearly and firmly, to communicate your and your family member's need for services and benefits.

Understanding what services and benefits are available to you and your family member will help you feel more confident in advocating for them. That's what this module is all about.

The information in this module is current as of its publication. Information on services and benefits changes from time to time. Please check with your Point of Contact (POC) (see Chapter 1) for updated information. He or she can also advise you about where to look for information you need.

You can start your search with these main Web sites:

- www.tricare.mil
- www.health.mil
- www.va.gov

If your service member/veteran has passed away due to his or her military injuries incurred during active military duty, you will surely have many questions to consider in the midst of your grief. As a survivor, you are eligible for special benefits. You can learn more about survivors' benefits at http://www.vba.va.gov.

x Module 4 Summary

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Navigating Services and Benefits xi

Design & Editing Update

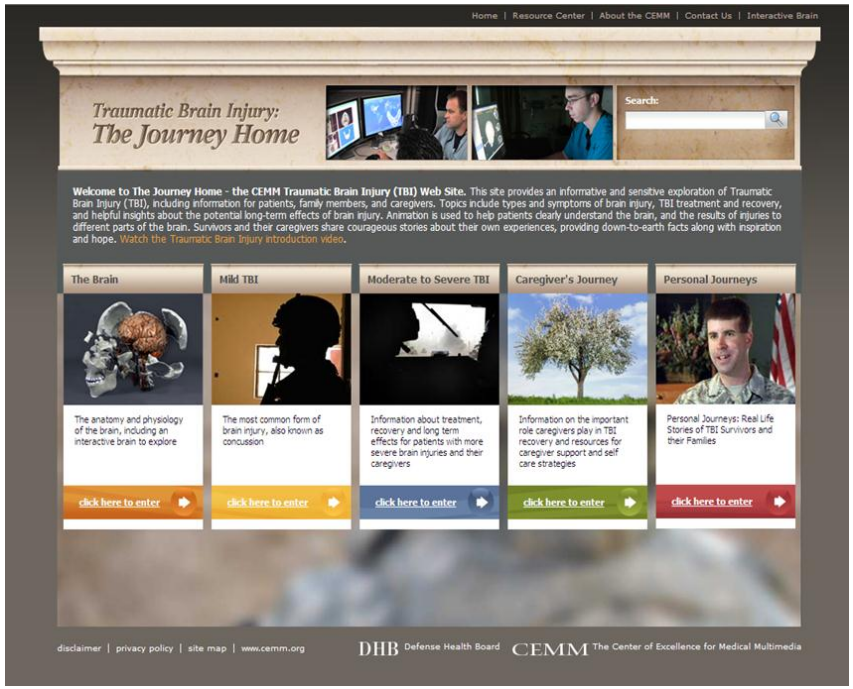
- Ongoing coordination with CEMM to ensure design and content continuity between print and on line versions.

Design & Editing Update

- Mild TBI Patient Education Guide
- Informal survey of existing products
- Goal for ~ 20-25 page product addressing complexities of mild TBI and overlay of PTSD, depression, combat stress, etc.
  - Aug. 15, 2009 – experts finalize content
  - Aug. 20, 2009 – to HJF Graphics for layout, graphics
  - Sept. 15, 2009 – distribute to Panel members
  - Oct. 14, 2009 – panel approval of content/layout, determination of marketing & distribution plans

Multi-media Update

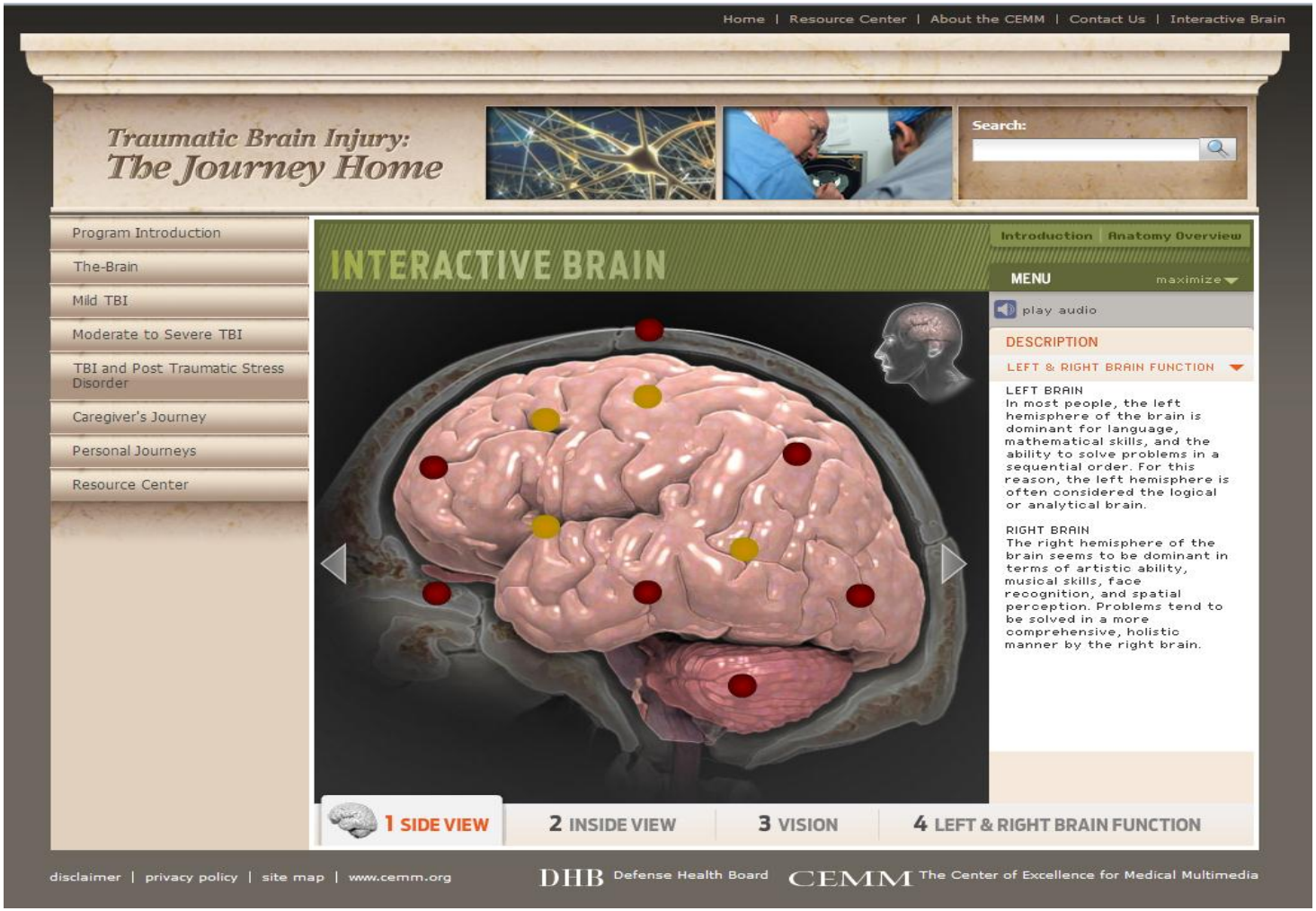
- CEMM to assure web site covers all curriculum topics
- “The Caregivers Journey” button on CEMM web site
- Curriculum modules to be posted as pdf’s on site



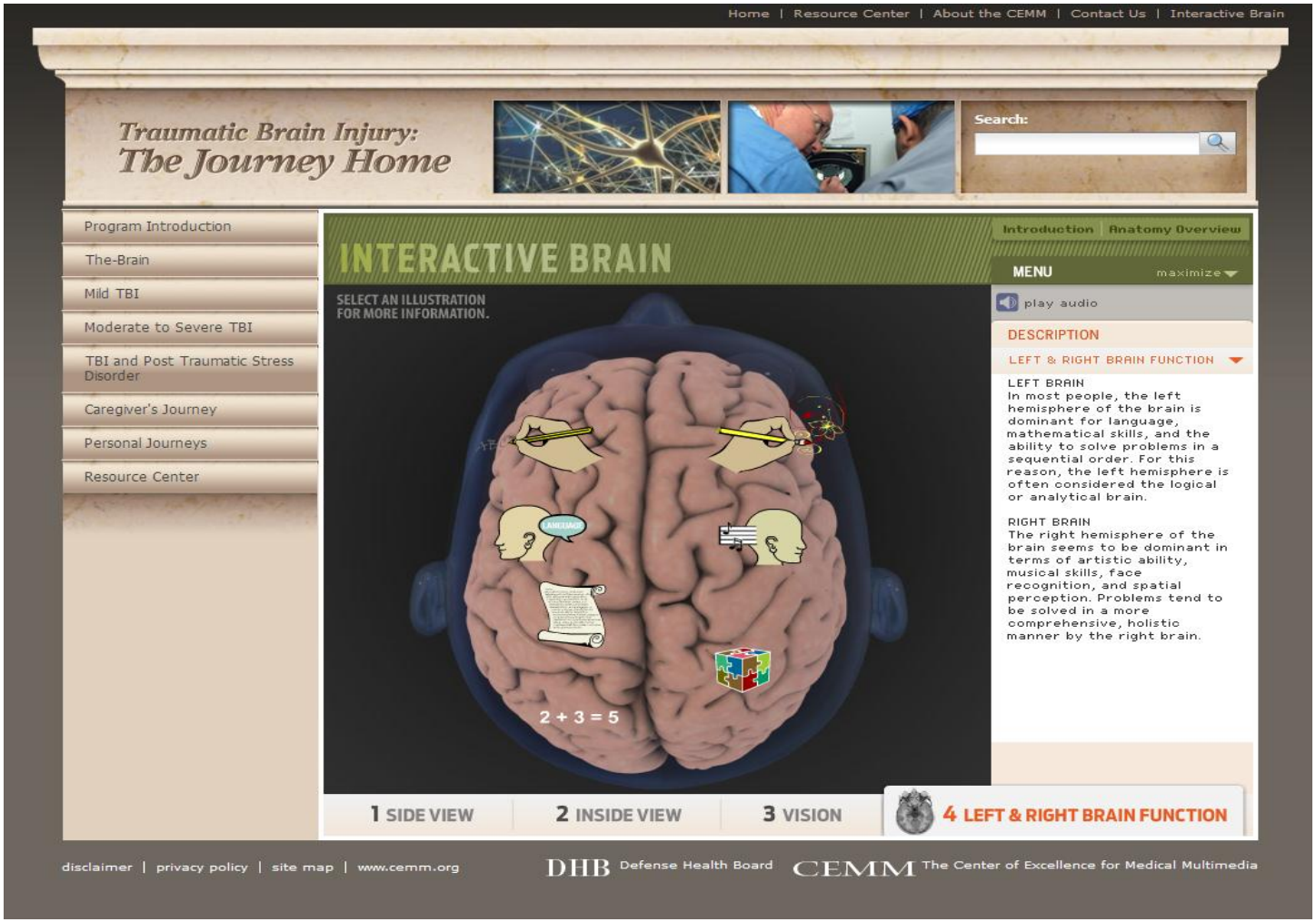
Multi-media Update

- CEMM Website launched June 2009
- http://www.traumaticbraininjuryatoz.org
- “Caregiver’s Journey” button was formatted to visually match the cover of the curriculum such that it is easily recognizable by the caregiver as complementary to the written product.
- The “Caregiver’s Journey” section of the website will continue to evolve to include additional vignettes and interactive components as we continue to work with CEMM

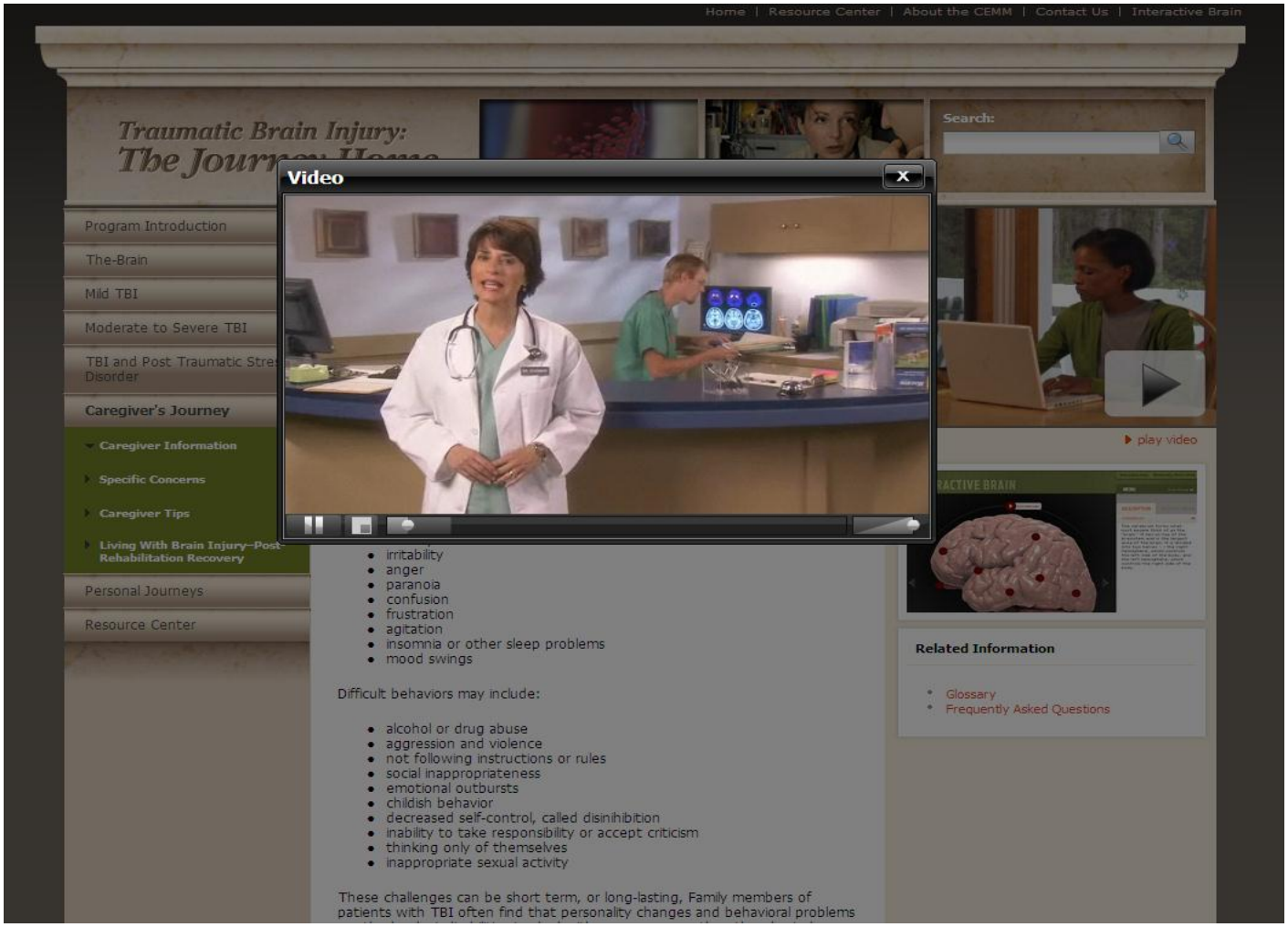
Interactive Multi-Media



Interactive Multi-Media



Interactive Multi-Media



Qualitative Process Review Update

- A contract bidding process contract bidding process resulted in the selection of Alan Newman Research, based in Richmond, VA.
- Groups homogeneous in service and heterogeneous in: geographic location, relationship to patient, severity of TBI, time since injury, and status (Active Duty, Veteran, Reserve, and Guard)
- 4 Sites: Tampa VA, FL; Fort Bragg, NC; WRAMC, Washington DC; San Diego Naval Medical Center, CA
- Goal of 50 total participants

Qualitative Process Review Update

- Focus groups initially scheduled the weeks of 20 July and 27 July
- Groups put on hold because a complaint was submitted to Tricare Management Activities and the Human Research Protections Office of the U.S. Army Medical Research and Materiel Command regarding failure to obtain IRB approval for the conduct of focus groups to obtain consumer feedback on the curriculum.
- DVBIC prepared a formal response to the complaint and on July 17, 2009, Dr. Brosch, Deputy Office of Research Protections responded that the project was not research and that their file would be closed.

Qualitative Process Review Update

- Groups scheduled: July 27-August 07, 2009
- Aug. 7, 2009 Focus groups completed
- Aug. 21, 2009 Receipt of detailed oral report from contractor
- Sep. 7, 2009 Receipt of written report from contractor August 15, 2009

Dissemination Update

- Identify audiences, end users
- Need to determine who and when the curriculum will be given to families
- Recommendations:
  - Command to receive a tri-fold tool summarizing purpose, contact information, important phone numbers and web sites.
  - Provider instruction on use prior to curriculum being provided to families
  - Need for timely and massive marketing campaign
  - Separate dissemination for mild TBI Patient Education Guide needed

October 13-14, 2009
Panel Meeting Agenda

- Final approval of curriculum Modules 1-4 and Caregiver Companion
- mTBI Patient Education Guide review and approval
- Approve marketing and distribution plan curriculum and mTBI Patient Education Guide
- Recommend plan for maintenance of curriculum content

Timeline

- July 27, 2009 — Focus groups commence
- Aug. 7, 2009 — Focus groups completed
- Aug. 21, 2009 — Receipt of detailed oral report from contractor
- Sep. 7, 2009 — Receipt of written report from contractor
- Sept. 30, 2009 — Curriculum revisions complete
- Oct. 14-15, 2009 — Final panel meeting & approval of curriculum
- Oct-Nov., 2009 — Forward final curriculum and mTBI Patient Education Guide to DHB
- Nov. 12-13, 2009 — Curriculum approval by DHB
- Dec. 1, 2009 — Dissemination of curriculum begins
- Dec. 31, 2009 — Final report to Congress

TBI Family Caregiver Panel

Questions?