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For Psychological Health  
& Traumatic Brain Injury

# **Effects of Chronic Mild TBI: Caregiver Perspectives and Knowledge Gaps**

**October 8, 2015; 1-2:30 p.m. (ET)**

**Presenter:**

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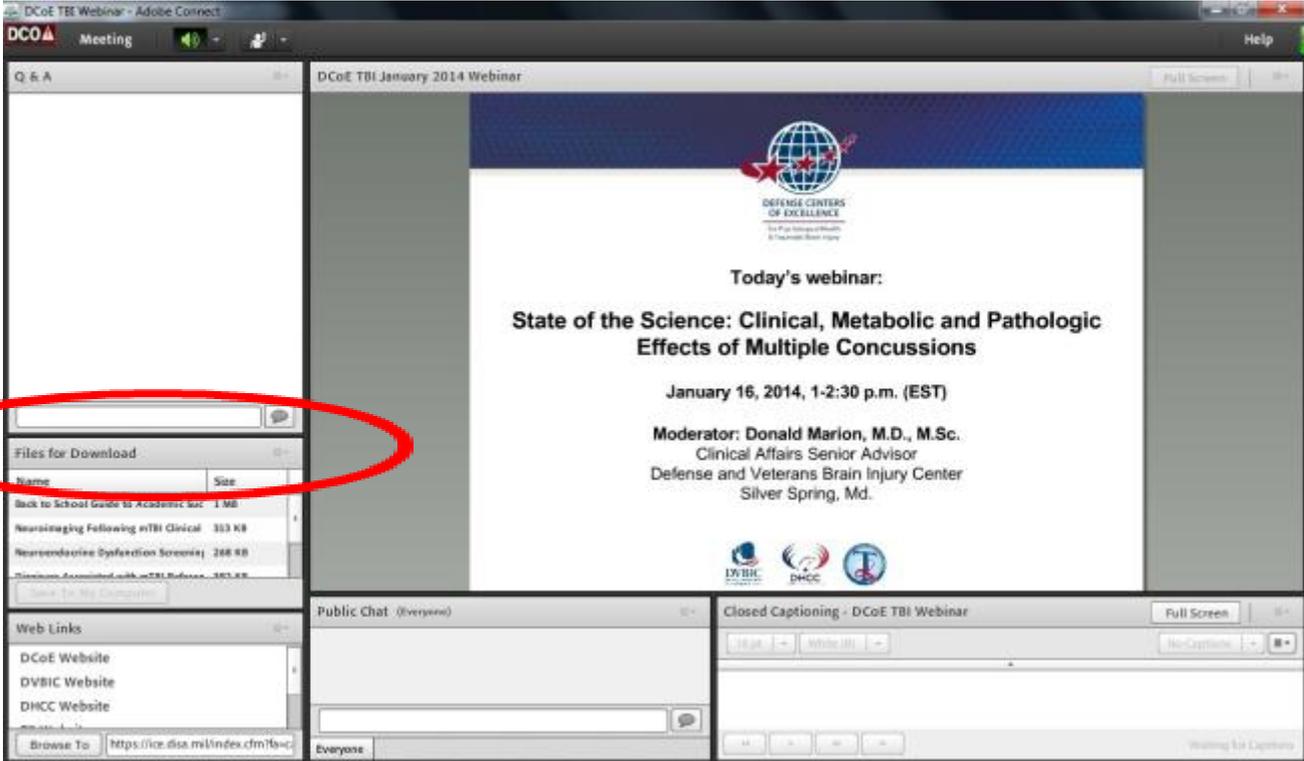


# Webinar Details

- Live closed captioning is available through Federal Relay Conference Captioning (see the “Closed Captioning” box)
- Webinar audio is **not** provided through Adobe Connect or Defense Connect Online
  - Dial: CONUS **888-455-0936**; International **773-799-3736**. Use participant pass code: **1825070**
- Question-and-answer (Q&A) session
  - Submit questions via the Q&A box

# Resources Available for Download

Today's presentation and resources are available for download in the "Files" box on the screen, or visit [dvbic.dcoe.mil/online-education](http://dvbic.dcoe.mil/online-education)



The screenshot displays a webinar interface with several panels. The main content area features the Defense Centers of Excellence logo and the following text:

**Today's webinar:**  
**State of the Science: Clinical, Metabolic and Pathologic Effects of Multiple Concussions**  
January 16, 2014, 1-2:30 p.m. (EST)  
Moderator: Donald Marion, M.D., M.Sc.  
Clinical Affairs Senior Advisor  
Defense and Veterans Brain Injury Center  
Silver Spring, Md.

Logos for DVBIC, DHCC, and the Department of Defense are visible at the bottom of the main content area.

The 'Files for Download' panel on the left is circled in red and contains the following table:

Name	Size
Back to School Guide for Academic Suc...	1 MB
Neuroimaging Following mTBI Clinical	353 KB
Neuroendocrine Dysfunction Screenin...	266 KB
Diagnosis Associated with mTBI Refere...	307 KB

Below the table is a 'Click to My Computer' button. The 'Web Links' panel below it lists 'DCoE Website', 'DVbic Website', and 'DHCC Website' with a 'Browse To' field containing the URL <https://ce.dsa.mil/index.cfm?vc>.

# Continuing Education Details

- DCoE's awarding of continuing education (CE) credit is limited in scope to health care providers who actively provide psychological health and traumatic brain injury care to active-duty U.S. service members, reservists, National Guardsmen, military veterans and/or their families.
- The authority for training of contractors is at the discretion of the chief contracting official.
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# Continuing Education Accreditation

- This continuing education activity is provided through collaboration between DCoE and Professional Education Services Group (PESG).
- Credit Designations include:
  - 1.5 AMA PRA Category 1 credits
  - 1.5 ANCC nursing contact hours
  - 1.5 APA Division 22 contact hours
  - 1.5 ACCME AMA PRA Category 1 credits
  - 1.5 CRCC continuing hours
  - 0.15 ASHA, Intermediate level continuing hours
  - 1.5 NASW continuing hours

# Continuing Education Accreditation

## Physicians

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of Professional Education Services Group and the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury (DCOE). Professional Education Services Group is accredited by the ACCME to provide continuing medical education for physicians. This activity has been approved for a maximum of 1.5 hours of AMA PRA Category 1 Credits™. Physicians should only claim credit to the extent of their participation.

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This activity is approved for up to 1.5 hours of continuing education. APA Division 22 (Rehabilitation Psychology) is approved by the American Psychological Association to sponsor continuing education for psychologists. APA Division 22 maintains responsibility for this program and its content.

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Nurse CE is provided for this program through collaboration between DCOE and Professional Education Services Group. Professional Education Services Group is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. This activity provides a maximum of 1.5 contact hours of nurse CE credit.

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This activity will provide 0.15 ASHA CEUs (Intermediate level, Professional area).

# Continuing Education Accreditation

## **Occupational Therapists**

(ACCME Non Physician CME Credit) For the purpose of recertification, The National Board for Certification in Occupational Therapy (NBCOT) accepts certificates of participation for educational activities certified for AMA PRA Category 1 Credit™ from organizations accredited by ACCME. Occupational Therapists may receive a maximum of 1.5 hours for completing this live program.

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- Please note, **registration is required for each webinar** regardless if the participant has an existing PESG account.
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# Questions and Chat

- Throughout the webinar, you are welcome to submit technical or content-related questions via the Q&A pod located on the screen. **Please do not submit technical or content-related questions via the chat pod.**
- The Q&A pod is monitored during the webinar; questions will be forwarded to presenters for response during the Q&A session.
- Participants may chat with one another during the webinar using the chat pod.
- The chat function will remain open 10 minutes after the conclusion of the webinar.

# Summary

Family caregivers of service members (SM) that experience chronic effects of mild traumatic brain injury (mTBI) discern that their loved ones experience myriad cognitive, emotional and behavioral problems. Caregivers often experience many of these same issues, disrupting the family dynamics. They often feel marginalized by the medical system and conclude that their health care providers lack insight into their experience. Knowledge gaps also exist regarding what caregivers understand about mTBI and resources to help them manage symptoms and patient outcomes.

This webinar will address these issues and explore how education for caregivers, family, friends, and health care providers could potentially enhance treatment outcomes and caregiver success.

At the conclusion of this webinar, participants will be able to:

- Describe three primary issues that present as common themes among families dealing with chronic mTBI
- Articulate how inclusion of the caregiver in the care continuum can lead to increased support for the chronic mTBI patient
- Apply education as an intervention to reduce risk factors for persistent symptoms and negative outcomes

# Pam S. Sjolinder, MACE, CBIS



Pam S. Sjolinder, MACE, CBIS

- DVBIC Regional Education Coordinator at Intrepid Spirit One, National Intrepid Center of Excellence Satellite at Fort Belvoir, Fort Belvoir, Va.
- Teacher/facilitator in the 12-week faith-based REBOOT Combat Recovery course which addresses the spiritual wounds of war
- Served as life skills trainer in a residential rehabilitation facility working with active duty SM, veterans and their families dealing with TBI and posttraumatic stress disorder (PTSD)
- Certified Brain Injury Specialist and member of the Academy of Certified Brain Injury Specialists
- Education
  - M.A. in Christian Education, Union Presbyterian Seminary

# Disclosures

- The views and opinions expressed in this presentation are those of the presenter and do not represent official policy of the Department of Defense (DoD), the United States Army or DVBIC.
- The presenter does not intend to discuss the off-label/investigative (unapproved) use of commercial products or devices.
- The presenter has no relevant relationships to disclose.

# Polling Question #1

My discipline is:

- Primary care provider
- Rehabilitation provider (SLP, OT, PT)
- Psychologist
- Nurse
- Social worker/case manager
- Other



# Case Series Background

- Chronic mTBI affects the individual and the individual's spouse
- Spouse often assumes the role of caregiver and spends the most time with the patient
  - However, in general, caregiver spouses have minimal education or training specific to the role of caregiver spouse for mTBI.
- Creates increased stress to the couple and other family members
- Few studies exist describing the experience of caregiver spouses.
- Small case series to evaluate these issues for the population of caregiver spouses caring for individuals with mTBI

# Methods



Photo courtesy of Pam Sjolinder

- Caregiver spouses were enrolled in the Caregiver Program at Fort Belvoir Community Hospital.
- A qualitative survey was developed specifically for caregivers of patients with chronic mTBI to query issues.
- The survey included questions regarding spousal relationships, family relationships, changes in the caregivers, changes in identity, and issues of grief and support.
- Analyses were performed using a deconstructive methodology with thematic categorization.



# Hypothesis

- Caregiver spouses are affected tremendously by the patient's injury.
- Exploratory study is needed for qualitative understanding of this effect.



# Caregiver Survey Questions

# Caregivers' Perspective of Issues for SMs with TBI

- **Loss of identify**
- **Anger**
- **Isolation**
- Sadness
- Depression
- Paranoia
- Personality change
- Worthlessness
- Blame
- Survivor's guilt
- Loss of interest
- Fear of everything
- Fear of future
- Hyper vigilant

(Sjolinder, 2014)

# Caregivers' Perspective of Issues for Their Children

- Trouble understanding
- Fear
- Feeling to blame
- Taking on increased responsibilities
- Role reversal (child—caregiver)
- Sadness
- Isolation
- Sense of loss
- Embarrassment
- Fierce protectiveness
- Anger
- Defiance/rebellion



<http://www.defense.gov/Media/Week-in-Photos>  
U.S. Marine Corps photo by Lance Cpl. Reece E. Lodder

(Sjolinder, 2014)

# Issues for the Caregivers

## ■ **Burned out**

- Anger
- Jealousy
- Fear
- Loss
- Hatred
- Resentment
- Frustration
- Misunderstood
- Loneliness
- Lack of sympathy/empathy
- Invisible to others
- Guilt
- No longer a couple
- Missing pre-injury spouse
- Grief
- Longing for the past
- Walking on eggshells
- Always compromising
- Feeling unloved
- No longer a wife
- Isolation
- With Permanent Change of Station (PCS), primary resource (support group) disappears

(Sjolinder, 2014)

# Issues Related to Being a Couple

- **Intimacy problems**
- **Role reversals**
- Communication problems
- Loneliness
- Increased duties/roles
- Increased relationship stress
- Anger
- Jealousy (patient center of attention, caregiver lost in shuffle with overwhelming needs)

(Sjolinder, 2014)

# Caregivers' Issues With Friends and Family

- **You're over-protective**
- **Don't understand**
- **Unwilling to accept "new person" or re-frame the relationship**
- **Don't accept the gravity of the caregiver role**
- It's all in your head – there's nothing wrong with your spouse
- He/she should be better by now
- They're just faking!
- They should "suck it up"

(Sjolinder, 2014)

# Caregivers' Issues With Friends and Family *continued*

- Isolation from family/friends
- Friends/family avoid us
- They want to put us “in a box” to make it easier to deal with us
- They're judgmental, especially relating to medications and outburst behaviors.
- You're wasting your life staying with him/her.
- When are you going back to work (to both spouse and caregiver)?
- Why are you still with him/her?

(Sjolinder, 2014)

# Caregivers' Issues With Providers/Medical Care

- **They don't believe us**
- Hard to get a diagnosis
- Hard to get help/treatment
- Providers "pass the buck."
- Don't listen to us
- Being minimized/marginalized (sometimes harmful to patient)
- Rushed out the door
- Lack of empathy/sympathy
- Accused of non-compliance
- Patients need to be re-evaluated after a period of time, especially when there is new medical knowledge.

(Sjolinder, 2014)

# Caregivers' Issues With Providers/Medical Care *continued*

- Physical wounds take priority over invisible wounds (invisible often neglected).
- Provider sees ONLY black or white.
- Secondary physical symptoms attributed to inappropriate behavior or judgment (i.e., peripheral neuropathy attributed to alcohol use)
- HIPPA violations, gossiping, oversharing of patient information to detriment of patient
- Long-term treatment leads to familiarity, diluting care and leading to inappropriate personal comments and advice.

(Sjolinder, 2014)

# What Caregivers Fear Most

- The future
- Loved one's safety
- Retirement (SM)
- Dementia (SM)
- Regression (SM)
- Loss of career (both)
- Our own "bad" behavior resulting from stress
- Being stuck in this "hole" forever
- No support
- Alone against the world
- Leaving the "Belvoir Bubble" (support group)

(Sjolinder, 2014)

# Caregivers' Perspective on SM Losses

- **Identity**
- Self
- Pride
- Job
- Autonomy
- Independence
- Respect
- Cognitive skills
- Relationships
- Male role
- Intimacy

(Sjolinder, 2014)

# Caregivers' Perspective on Child's Losses

- Their Mom or Dad
- Their childhood
- Their innocence
- Their independence
- Their family unit
- Will never know their “real” parent (especially very young children)
- Having only “kid” things on their mind

(Sjolinder, 2014)

# Caregiver's Losses

- **My SELF**
- **Intimacy**
- My life
- My home
- My career
- My kids
- My spouse  
(*ambiguous loss*)
- My independence

(Sjolinder, 2014)

Ambiguous loss describes a situation in which a loved one is absent in some ways but present in others. The person can be present physically, but is not participating in family life. (Zayfert & DeViva, 2011)



# Summary of Common Themes

- SM patients are **angry**, **isolated**, and feel that they've **lost who they are**.
- Their children don't understand, are fearful sad and **angry** – feel **isolated** and their childhood **roles have changed**.
- The caregiver is burned out, feeling **lonely**, **isolated**, **angry**, invisible, frustrated, and **no longer a wife**.
- As a couple – **loss of intimacy** (can cause **emotional isolation**) and **role reversal** are greatest issues.

(Sjolinder, 2014)



# Summary of Common Themes *continued*

- Family and friends don't understand, are judgmental and **isolate** SM patient and caregiver from them.
- Caregivers perceive that providers often don't believe them, making caregivers feel marginalized, minimized, and unheard (essentially **isolating** the caregiver from the care continuum).
- SM patients have **lost their identity**, caregivers have **lost themselves**, and children have **lost their childhood**.

(Sjolinder, 2014)

# Common Issues

- Anger
- Loss of Identity
- Isolation

# Isolation Perceived

**Isolation**—the experience of being separated from others—may result from being physically removed from others, as when a person lives in a remote area, or it can result from the *perception* of being removed from a community, such as when a person *feels* socially or emotionally isolated from others.

When a person experiences too much solitude or feels socially isolated from others, he or she may develop feelings of *loneliness*, social anxiety, helplessness, or depression.

(Hawthorne, 2008)



# Perceived Isolation = Loneliness

“**Loneliness** is a situation experienced by the individual as one where there is an unpleasant or inadmissible lack of (quality of) certain relationships. This includes situations in which the number of existing relationships is smaller than is considered desirable or admissible, as well as situations where the intimacy one wishes for has not been realized.” (De Jong Gierveld, 2006)

- **Emotional Loneliness** – stemming from the absence of an intimate figure or a close emotional attachment (partner, best friend) (*loss of intimacy*)
- **Social Loneliness** – stemming from the absence of a broader group of contacts, or an engaging social network

## **Perceived social isolation and loneliness may lead to:**

- Depression, chronic health conditions, poor long-term health outcomes, early death & suicide (Hawthorne, 2008)

# Feeling Lonely Around People

After injury, many survivors describe feeling lonely – even when they are surrounded by other people. This loneliness may arise for many different reasons.

- **Difficulty talking to other people** or understanding what others are saying
- Many survivors **feel self-conscious** after their injuries.
- Many survivors **worry about what others will think of them** and may **feel nervous** about being around other people.
- Many survivors notice they are **more irritable after their injuries.**
- **Fatigue and low energy** are common problems after brain injury.

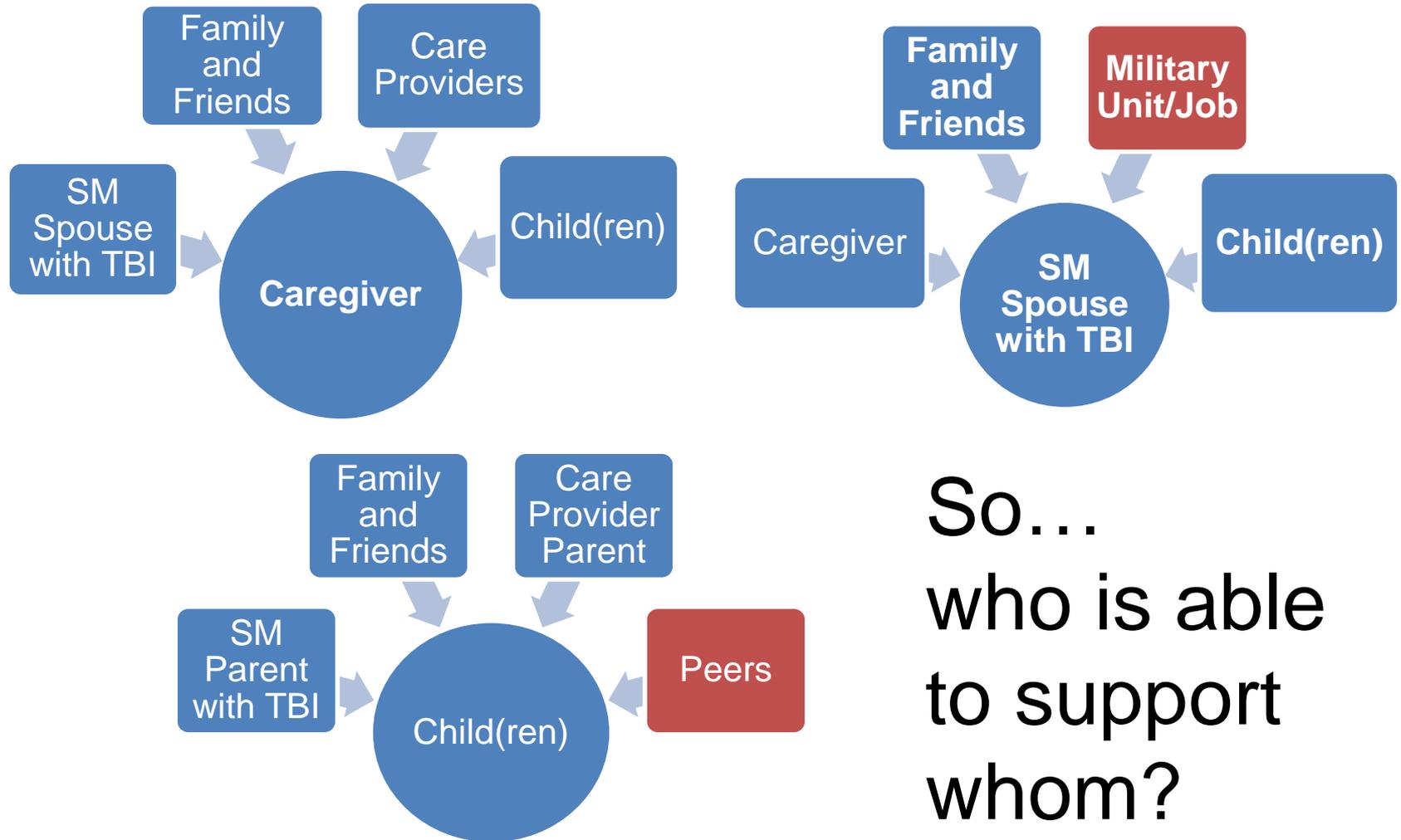
(Kreutzer, Taylor, & Livingston, 2005)

# Feeling Lonely Around People *continued*

- **Pain and other physical problems** often make it harder for survivors to do things they used to enjoy.
- Many survivors are **not able to drive** or work after their injury.
- People generally **make friends through work or being involved in social or recreational activities.**
- **Friends and family may feel uncomfortable** because they don't know what to say, how to act, or how to help.

(Kreutzer, Taylor, & Livingston, 2005)

# Everyone Feels Isolated



So...  
who is able  
to support  
whom?

# Caregiver Support System Losses After TBI

- Loved ones (patient)
- Family
- Friends
- Children
- Providers

(Sjolinder, 2014)

# Contributing Factors of Social Isolation

Factors contributing to social isolation include **loss** (in its many forms), **poor physical health**, mental illness, low morale, **being a caregiver**, **geographic location**, **communication and transport difficulties** (Findlay, 2003)

Many of these factors are often beyond the socially isolated person's control and are therefore not obviously susceptible to amelioration. (Wenger, Davies, Shahtahmasebi, & Scott, 2008)

Thus, **designing effective interventions to address the problem is difficult.**

# Table C-2. Risk Factors for Persistent Symptoms and/or Poorer Overall Outcomes

Pre-injury	Peri-injury	Post-injury
<ul style="list-style-type: none"> <li>▪ <b>Age (older)</b></li> <li>▪ <b>Gender (female)</b></li> <li>▪ Low SES</li> <li>▪ <b>Less Education/Lower levels of intelligence</b></li> <li>▪ Pre-neurological conditions</li> <li>▪ <b>Pre- or co-occurrence of mental health disorders (depression, anxiety, traumatic stress, or substance abuse)</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Lack of support system</b></li> <li>▪ Acute symptom presentation (e.g., headaches, dizziness, or nausea in the ER)</li> <li>▪ Context of injury (stress, combat-related, traumatic)</li> </ul> <p>•<i>Bold text indicates support of Level C evidence</i></p>	<ul style="list-style-type: none"> <li>▪ <b>Compensation</b></li> <li>▪ <b>Litigation</b> (malingering, delayed resolution)</li> <li>▪ <b>Co-occurrence of psychiatric disorders</b></li> <li>▪ Co-occurrence of chronic pain conditions</li> <li>▪ <b>Lack of support system</b> (emphasis mine)</li> <li>▪ <b>Low education</b></li> </ul>



# Assessing for Lack of Support/Loneliness

Assessment of the patient with concussion/mTBI should include a detailed history regarding potential pre-injury, peri-injury, or post-injury risk factors for poorer outcomes:

- *At peri -and post-injury, assess for lower levels of or less available social support*

(VA & DoD, 2009)

# Evidence Statement

## ***Social Support***

Lower level of social support or higher level of psychosocial stress are risk factors for long-term post-concussive symptoms

(VA & DoD, 2009)

# Polling Question #2

I/my site routinely assess for lower levels of or less available social support for:

- The patient
- The family
- The patient and family
- Neither the patient nor the family
- N/A
- Not known



# Negative Support

Potentially modifiable psychosocial barriers to patient functioning could include the following:

- **Living environment**—Homelessness can perpetuate chronic illness as the result of environmental exposure and virtually non-existent personal hygiene.
- **Support systems**—**Negative supports on the part of the spouse, family, or significant other can impair and even worsen functionality.**
- **Job**—Work place factors have been associated with illness-related behavior.
- **Finances**—Disability compensation can perpetuate illness by requiring continuing symptoms and disability for the worker to be eligible for benefits.

# Contributing Factors to Negative Support for SM

When caregivers walk in our clinics many are often feeling:

- **They have lost EVERYTHING**
- Angry
- Fearful
- Mournful
- Resentful
- Frustrated
- Misunderstood
- Lonely
- Invisible
- Burned out
- Guilty
- Sad
- Isolated
- Jealous
- Lost
- Separated from SM and all support
- Their children have lost their childhood

(Sjolinder, 2014)



# **Include the Caregiver in the Care Continuum to Increase Support for the SM**

# Why is the Caregiver Often Not Involved in Treatment?

- SM's choice (HIPPA)
- SM wants to keep symptoms hidden from provider
- Provider's choice
- Family logistics
- Family in crisis



# Caregiver Perspective of Inclusion

- Often unaware of disciplines and services that SM is receiving
- Much of the knowledge of their SM's care comes directly through the SM.
- Desire to know more about the care their loved one is receiving – they want to help and support but feel left out
- Believe that they could “carry over” therapies/homework into the home environment
- Believe that their input is very valuable for the care team to know



# Potential Benefits of Caregiver/Family Inclusion

- Often they knew the SM before their injury and can verify cognitive, physical and behavioral changes.
- They are keenly aware of exhibited symptoms and behaviors.
- They hear their loved one's unfiltered comments.
- They may have an instinctive sense of what their loved one needs.
- They have history on the patient.
- They are sometimes aware of symptoms when the service member is not.
- They are aware of medication reactions that SMs may not report to provider.
- Sense of inclusion may move caregiver from an adversarial to an advocacy role, minimizing caregiver's negativity.

# Methods of Inclusion in Care Continuum

- Educate providers on the issues facing caregivers and their children.
- Providers encourage patients to be open to caregiver participation in care.
- Develop ways to keep caregiver “in the loop” –
  - Attending appointments
  - Providing/developing resources/education for caregivers on specific treatments, symptoms and behaviors
  - Keeping family informed of medical advances and new research (diminish fears)
- Assure caregivers that their input is heard and valued.



# Exclusion is a Perceived Barrier to Care

“There still are difficulties with getting treatment, and that making sure the caregiver is an equal part of that treatment is critical. Thirteen years into it, I need people to understand that not all injuries are visible and not all barriers to getting to treatment are physical barriers. **"As a caregiver to a person that suffers memory loss, if (doctors) don't talk to me, you get half the picture you need for treatment."**

Andrea Sawyer, whose husband, Sgt. Loyd Sawyer, was diagnosed with TBI and PTSD, spoke firsthand on the difficulties faced by caregivers on June 24, 2015 at the American Legion Symposium "Advancing Care and Treatments for Veterans with TBI and PTSD" at the Institute of Medicine in Washington, D.C



# **Education as an Intervention for Increasing Support for Chronic mTBI Patients**

# Decrease Caregiver and Family Isolation and Increase Patient Support

**By:**

- Providing TBI symptom and behavioral education to the caregiver and child(ren) in both acute and chronic phases
- Teaching the caregiver how to teach TBI symptom and behavioral education to extended family and friends
- Participating in support groups



# Support Groups Reduce Social Isolation

**Support groups:** The types of support groups that have been evaluated include **educational** and **friendship enrichment** or **empowerment** programmes and discussion groups. The research shows that support groups can have a **positive effect on social isolation** if they have an implementation period of **at least five months**.

(Findlay, 2003)

# Education for Acute Concussion

**Early education of patients and their families (*printed material combined with verbal review*) is the best available treatment for concussion/mTBI and for preventing/reducing the development of persistent symptoms.**

(VA & DoD, 2009)



# TBI “Facts” According to Caregivers

- A life-changing event
- If not resolved in six months, then treatment is needed
- Will be dealing with it your entire life
- TBIs are cumulative
- Without treatment, symptoms get worse – can lead to death (second impact syndrome), chronic traumatic encephalopathy (CTE)
- Requires more sleep (tired brain)
- TBI and PTSD go hand-in-hand
- At risk for peripheral damage
- Impulsivity
- Causes behavioral issues and personality changes
- Balance and vestibular issues
- Intimacy disappears
- Visual and cognitive processing issues
- Loss of high executive functioning

(Sjolinder, 2014)



# What Do You Want to Learn About TBI?

- How to care for it
- Best care for best function/outcome
- Adaptive technology
- Long-term outcomes (CTE, dementia, etc.)
- How to live with TBI (family/friends)
- New medicine/new knowledge
- Long-term care options
- Transitional care options
- Community-based options
- How to deal with the VA (retirement/Med Boards)
- **How to educate family and friends**

(Sjolinder, 2014)



# What Do You Want to Learn About Caregiving?

- Survival skills
- How to differentiate roles (wife vs. caregiver)
- How to accept what has happened
- How to relinquish caregiver job without losing control of spouse
- Hand off/share care
- How to caregive and not feel like his/her parent
- How to respond when others attack or negate invisible wounds

(Sjolinder, 2014)

# What Do You Want to Learn About Caregiving? *continued*

- How to maintain sense of self
- How to regain, maintain and continue intimacy
- **How to effectively communicate with providers**
- How to effectively communicate with loved one during confrontation (de-escalation)
- How not to take bad behavior personally
- How to manage the patient's need for independence, which could lead to unsafe situations (so we don't have to worry so much)

(Sjolinder, 2014)



# Symptom and Behavioral Education for Caregivers and Families

- Screen new patients, their caregivers/families for levels of isolation/loneliness and identified for specific education follow-up.
- Determine whether it would be more advantageous to set up individual, couples or family education meetings.
- Review notes, provider summaries.
- Pull resources that pertain to diagnosis and known issues.
- Obtain caregiver perspective of issues, behaviors, and support.
- Provide education on these symptoms and behaviors.
- Suggest ways to apply their “new TBI knowledge” in helping to understand and deal with behaviors.

***Goal: Move the caregiver/family from an adversarial role to becoming an advocate for the patient***

# Couple TBI Education

Question to SM:

*“Do you have any problems with your memory?”*

Answer:

*“No...none.”*

Caregiver's

Response:



Photo courtesy of Pam Sjolinder



Photo courtesy of Pam Sjolinder



# Case #1

- Caregiver mother and two sons ages 15 and 20
- All distressed that SM patient had pulled away from family
- Didn't understand why SM not interested in doing things together as a family anymore
- Caregiver worried about children
- Older son trying to be parent to make up for his father's "absence"
- Younger son angry and sad – he needs his father

# Case #2

- Caregiver with one small child
- Dealing with behavioral changes and mood issues
- SM patient dealing with very little sleep; irritable, impatient
- SM receiving sleep hygiene instruction as part of his rehab
- Caregiver claims that SM not working on making any changes to his sleep hygiene at home

# Potential Benefits of Caregiver Education

- More support for the SM patient may reduce factors for persistent symptoms and/or poorer overall outcomes.
- Feeling hopeful about the future
- Caregiver input helpful to treatment team
- Assist with treatment compliance
- Improved family issues may lead to positive lifestyle changes.



<http://www.defense.gov/Media/Week-in-Photos/p/1>

# Resources for Caregiver Education

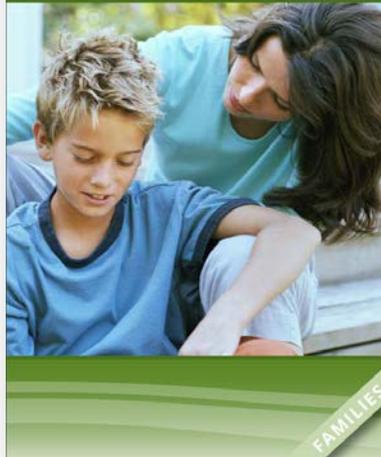
## *continued*

Taking Care of Yourself  
While Caring for Others



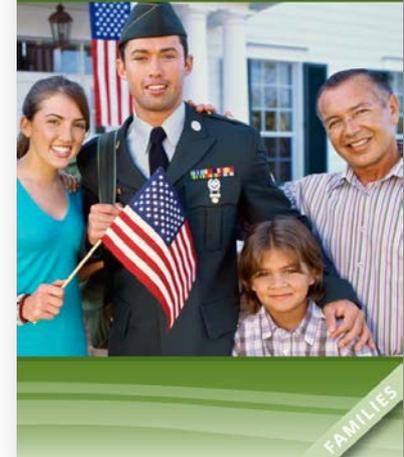
Coping techniques for caregivers and families who are trying to manage stress, anxiety or sadness, while caring for an injured SM/veteran.

Talking With  
Children About TBI



Offers communication techniques that can help you explain the effects of TBI to children in a way they can understand. For every age group, from toddlers to teens.

Addressing Family Needs



Essential to families with a SM/veteran with a TBI. Everyone in the family is affected, and this tool will assist during this time of transition.

<http://dvbic.dcoe.mil/resources>

# Resources for Caregiver Education

## continued

**Signs and Symptoms**  
Concussion/Mild Traumatic Brain Injury

**DEFINITION:**  
A traumatic brain injury (TBI) is a blow or jolt to the head that disrupts the normal function of the brain. The severity of the TBI is determined at the time of the injury and may be classified as mild, moderate or severe.

**COMMON SIGNS AND SYMPTOMS:**

<b>Physical</b>	<b>Cognitive</b>
Headache	Sweating/flushing
Sleep disturbances	Poor concentration
Dizziness	Nausea/vomiting
Balance problems	Difficulty finding words
Memory loss	Confusion
Fatigue	Feeling anxious
Visual disturbances	Feeling depressed
Light sensitivity	Irritability
Ringing in ears	Blood clots

**Did you know?**  
Concussion – similar to a mild TBI – is the most common form of TBI to show secondary symptoms of concussion effects weeks and/or even months later.

**PATIENTS**

This fact sheet identifies major physical, cognitive and emotional symptoms of concussion and provides coping and recovery tips.

**Help With Ongoing Symptoms**  
Concussion/Mild Traumatic Brain Injury (mTBI)

Most people with concussion recover after their injury. However, a small percentage of people will experience symptoms (such as headaches, memory problems, irritability or fatigue) for a longer period of time. Although these symptoms might be related to the concussion, they often are caused by other issues or factors that lengthen the recovery period. These factors can include age, genetic, previous history of concussion, the presence of a psychological disorder or a learning disability, stress or burnout at work, and certain medications. Remember, not all symptoms improve at the same rate – some take longer than others.

**Here's what you can do:**

- Speak up. It's important to communicate honestly and openly with your health care provider about symptoms that continue to bother you or interfere with your everyday life.
- Keep track of your symptoms. Track ongoing changes in your symptoms, or any new symptoms in a journal or mobile application tool such as eMoodPad. Share these changes with your health care provider to propose possible causes and treatment options.
- Support your recovery. Think about ways to help your brain and body heal now. Eat healthy foods, exercise and keep a regular sleep schedule. Go to sleep and wake up at the same time every day. Limit caffeine, especially energy drinks, which can hurt the quality of your sleep. Limit alcohol consumption.
- Seek ways to relax. Reduce stress by trying activities such as yoga, meditation, music or art. Talk with your health care provider about these options to complement your treatment.

*Concussion often improves differently than you expect, and as your medical and psychological conditions, and relieve your worries. Remember to be patient and work closely with your provider.*

**PATIENTS**

This fact sheet addresses why symptoms continue to persist in some patients and how they can cope or seek additional help.

**Concussion/Mild Traumatic Brain Injury and Posttraumatic Stress Disorder**

**WHAT IS A TRAUMATIC BRAIN INJURY (TBI)?**

- A TBI is the disruption of normal brain function caused by an external force (including a jolt or blow to the head).
- Not all blows or jolts to the head cause a TBI.
- A TBI may be classified as mild, moderate or severe. A mild TBI, also called a concussion, is the most common form.
- You may or may not lose consciousness, remember the event (amnesia), feel confused or "not start" immediately after the injury.

**WHAT IS POSTTRAUMATIC STRESS DISORDER (PTSD)?**

PTSD often has a group of symptoms that may develop after you are exposed to actual or threatened death, serious injury or sexual violence. These events can include direct exposure, domestic violence, sexual, mental or physical abuse, a motor-vehicle crash, a terrorist attack, or a natural disaster.

**IS THERE A CONNECTION BETWEEN CONCUSSION AND PTSD? CAN I HAVE BOTH?**

- Yes. Concussion and PTSD involve physical changes and psychological symptoms.
- Yes, you can have both. Concussion and PTSD can be caused by the same traumatic event.
- Some people with a concussion may also have PTSD, but not everyone does.
- The symptoms of PTSD and concussion may be similar and make it hard to tell which condition you have.
- Common symptoms for each are listed below.

**Overlapping Symptoms**

<b>Possible Symptoms of TBI</b>	<b>Overlapping Symptoms</b>	<b>Possible Symptoms of PTSD</b>
<ul style="list-style-type: none"> <li>• headaches</li> <li>• dizziness/balance problems</li> <li>• fatigue</li> <li>• irritability</li> <li>• sensitivity to light and sound</li> <li>• vision changes</li> <li>• impulsivity</li> </ul>	<ul style="list-style-type: none"> <li>• fatigue</li> <li>• sleep problems</li> <li>• trouble with memory and attention</li> <li>• feeling depressed</li> <li>• irritability</li> </ul>	<ul style="list-style-type: none"> <li>• on high alert</li> <li>• startled easily</li> <li>• flashbacks</li> <li>• nightmares</li> <li>• guilty feelings</li> <li>• avoidance</li> <li>• numbness</li> <li>• self-destructive behavior</li> </ul>

*Concussion often improves differently than you expect, and as your medical and psychological conditions, and relieve your worries. Remember to be patient and work closely with your provider.*

**PATIENTS**

This fact sheet defines concussion/mild traumatic brain injury and posttraumatic stress disorder and explains how overlapping symptoms often occur. It also describes why it's important to seek out treatment for both conditions and provides helpful advice on what to tell your family and friends to help in the recovery process.

<http://dvbic.dcoe.mil/resources>

# Resources for Caregiver Education

## *continued*



Images courtesy of DVBC

## Mild TBI Symptom Management Fact Sheets

These fact sheets can be used by health care providers to educate patients with concussion/mild TBI on how to manage symptoms related to their injury.

- Behavior, personality or mood changes
- Head injury and dizziness
- Headache and neck pain
- Healthy sleep
- Memory issues

<http://dvbic.dcoe.mil/resources>

# Resources for Caregiver Education

## *continued*

**Family and Friends**

Family members and friends play an important role in the care and rehabilitation of individuals with traumatic brain injuries (TBIs). Most people who have sustained a TBI recover significantly in the first few months following injury. In fact, more than 85 percent of people with a concussion, also known as a mild TBI, recover completely within weeks to months with minimal intervention.

Those with moderate, severe, or penetrating injury are also expected to make some improvement, although the recovery process in these cases may take longer and be more unpredictable. The social support friends and family give plays an important role in the recovery of those with TBI. This section is devoted to families and friends, who play a critical role in supporting the health and well-being of individuals with TBI recognizing the emotional, physical and financial toll that is so often associated with caregiving.

TBI may cause physical, cognitive and behavioral changes that can be difficult to adapt to for both the individual and family members. These changes are usually temporary, but in some cases recovery becomes a lifelong process of adjustments and accommodations for the injured person and the family. People with TBI can lead joyful and meaningful lives with the aid of friends and loved ones who can provide ongoing support and encouragement. Research has found a direct relationship between a family's ability to adapt and cope with trauma and the patient's success with rehabilitation and reintegration.

Milder symptoms may require family members to adapt only to a few changes in their loved ones. More severe symptoms may require family members to take on the role of caregiver, or share that responsibility with others temporarily or on a continual basis.

Family members and care givers may request support from DVBIC's TBI Recovery Support Program.

**Get Help Now**  
These lines are staffed 24/7.

**Military Crisis Line**  
800-273-8255, press 1

Traumatic Brain Injury, Psychological Health Help: DCoE Outreach Center  
866-966-1020

**Learn About Brain Tissue Donation** »  
The Department of Defense has established a brain tissue repository as an important resource to advance traumatic brain injury (TBI) research. The results of this research will benefit individuals in the future who sustain TBIs.

**National Resources** »  
Organizations and Web resources that offer services, information, and support for service members, veterans, health care providers, and families.

**Educational Resources** »  
Fact sheets, guides, posters, and more about brain injury for service members, veterans, health care providers, and family members. All materials are available free of charge.

## DVBIC Family and Friends

Family members and friends play an important role in the care and rehabilitation of individuals with TBI. Explore topics on this site that offer help for caregivers, families, and friends.

Image courtesy of DVBIC

<http://dvbic.dcoe.mil/audience/family-friends>

# Resources for Caregiver Education

## *continued*



Image courtesy of afterdeployment

## AfterDeployment Website

Information and multimedia resources to address common psychological health concerns or challenges related to military deployments

**Website:** <http://afterdeployment.dcoe.mil>

## LifeArmor Mobile App

Provides information on 17 topics related to post-deployment to include anger, stress and anxiety, and substance abuse. Mobile companion to <http://afterdeployment.dcoe.mil>

**Website:**

<http://t2health.dcoe.mil/apps/lifearmor>  
veterans and military families

**Format:** Android and iOS



Image courtesy of National Center for Telehealth & Technology

# Resources for Caregiver Education

## *continued*

### Cognitive Behavioral Therapy for Insomnia (CBT-i) Coach App

Supplemental tool to be used during CBT-i between a patient and mental health professional to help patients adjust and maintain sleep routines and their approach to sleep

#### Download:

<http://mobilehealth.va.gov/app/cbt-i-coach>

#### Website:

<http://t2health.dcoe.mil/apps/CBT-i>

**Format:** Android and iOS



Images courtesy of National Center for Telehealth & Technology

# Resources for Caregiver Education

## *continued*

### **Concussion Coach Mobile App**

Provides users with information about concussion, a self-assessment instrument for symptoms and their severity, tools to help build resilience and manage symptoms, and recommendations for community-based resources and support

#### **Download:**

<http://mobilehealth.va.gov/app/concussion-coach>

#### **Website:**

<http://t2health.dcoe.mil/apps/ConcussionCoach>

#### **Format:** iOS



Images courtesy of National Center  
for Telehealth & Technology

# Resources for Caregiver Education *continued*

## Military Kids Connect ®

Online community that offers age-appropriate resources to support children from pre-deployment, through a parent's or caregiver's return. Includes informative activities, fun games and helpful videos

### Website:

<http://militarykidsconnect.dcoe.mil>

Image courtesy of Military Kids Connect®



Image courtesy of Sesame Street for Military Families

## Military Families Near and Far

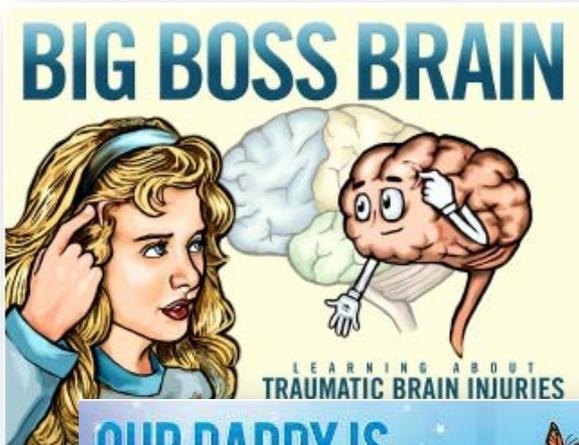
In conjunction with Sesame Street and the Electric Company, this website brings families together with useful resources and tools for military families.

### Website:

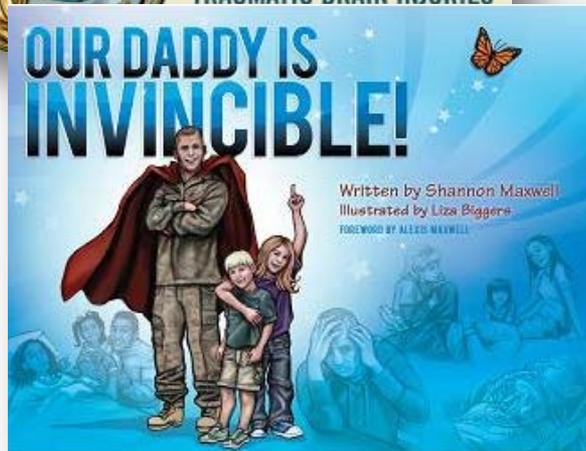
<https://www.familiesnearandfar.org/resources/injuries/>

# Resources for Caregiver Education

## *continued*



**Big Boss Brain** is an unprecedented look into the often invisible effects of TBI through the eyes of a child, answering questions about the physical, cognitive, and emotional/behavioral changes in a loved one following a TBI.



What happens when a parent becomes traumatically injured? **Our Daddy Is Invincible!** is based on the true story of a Wounded Warrior and American hero and his family.

Author, Shannon Maxwell

# Resources for Caregiver Education

## *continued*

**DEFENSE AND VETERANS BRAIN INJURY CENTER**

About DVBIC | About Traumatic Brain Injury | Education | Research | DVBIC Locations

Service Members & Veterans | Family & Caregivers | Medical Providers

### TBI Recovery Support Program

The Traumatic Brain Injury (TBI) Recovery Support Program (RSP) ensures that its clients are supported and connected – and stay connected – to appropriate resources as they progress through the entire continuum of care

#### Overview

DVBIC's Traumatic Brain Injury (TBI) Recovery Support Program (formerly known as the Care Coordination Program) assists service members, National Guard, reservists and veterans who have sustained a TBI, as well as their family members and caregivers, as they negotiate complex systems of care. The program's Recovery Support Specialists (RSSs) are assigned to 14 regions throughout the United States and Germany, provide a network for care coordination.

#### Mission

To optimize successful engagement, treatment and recovery from TBI by providing TBI expertise, resources and support to the military and veterans' communities while facilitating connections across the entire continuum of recovery and spectrum of care.

#### Services

- **Clients:** Connection to TBI and psychological health services, and non-medical resources. Recovery Support Specialists establish ongoing relationships with clients to empower them with resources that advance their care and understanding of TBI. Recovery Support Specialists:
  - Conduct regular follow-up interviews for 24 months
  - Track symptoms and monitor treatment compliance and outcomes
  - Identify local resources and programs
- **Transition clients** to another Recovery Support Specialist if clients relocate
- **Providers and Care Managers:** Information and access to TBI research, training and educational products

#### Eligibility

Service members, National Guard, reservists or veterans who have been diagnosed with a TBI, their family members and caregivers. A referral may be generated by:

- Case managers or providers at military and VA treatment facilities or civilian settings
- Self-referral, family members or caregivers
- Email to [mrmc.dcoe.tbirecoverysupport@mail.mil](mailto:mrmc.dcoe.tbirecoverysupport@mail.mil)
- To locate a TBI Recovery Support Specialist or to download the client brochure, visit the TBI Recovery Support Program at <http://dvbic.dcoe.mil/tbi-recovery-support-program>

**Traumatic Brain Injury Recovery Support Program**

ACTIVE DUTY GUARD & RESERVE VETERANS

Images courtesy of DVBIC

## TBI Recovery Support Program

Program and its recovery support specialists provide TBI expertise, support and connection to TBI and psychological health services

### Brochure:

[http://dvbic.dcoe.mil/sites/default/files/2014\\_TBI\\_RSP\\_Brochure.pdf](http://dvbic.dcoe.mil/sites/default/files/2014_TBI_RSP_Brochure.pdf)

### Fact sheet:

[http://dvbic.dcoe.mil/sites/default/files/DVBIC\\_TBI\\_Recovery-Support-Program\\_FactSheet\\_2015-02-19.pdf](http://dvbic.dcoe.mil/sites/default/files/DVBIC_TBI_Recovery-Support-Program_FactSheet_2015-02-19.pdf)

### Website:

<http://dvbic.dcoe.mil/tbi-recovery-support-program>

### Email:

[mrmc.dcoe.TBIrecoverysupport@mail.mil](mailto:mrmc.dcoe.TBIrecoverysupport@mail.mil)

# References

De Jong Gierveld, J., van Tilburg, T., & Dykstra, P. A. (2006). Loneliness and social isolation. In Vangelisti, A. and Perlman, D. (Eds), *Cambridge Handbook of Personal Relationships*. (pp. 485-500). Retrieved from New York, NY: Cambridge University Press

Findlay, R. A. (2003). Interventions to reduce social isolation amongst older people: where is the evidence?. *Ageing & Society*, 23, 647-658. doi: 10.1017/S0144686X03001296

Hawthorne, G. (2008). Perceived social isolation in a community sample: Its prevalence and correlates with aspects of peoples' lives. *Social Psychiatry and Psychiatric Epidemiology*, 43(2), 140-50. doi: 10.1007/s00127-007-0279-8

Kreutzer, J., Taylor, L. & Livingston, L. (2005). *Recovering Relationships After Brain Injury: The Essential Guide*. National Resource Center for Traumatic Brain Injury, Virginia Commonwealth Model Systems of Care

# References

Luis, C. A., Vanderploeg, R. D., & Curtiss, G. (2003). Predictors of postconcussion symptom complex in community dwelling male veterans. *Journal of the International Neuropsychological Society*, 9(7), 1001-15. doi: 10.1017/S1355617703970044

McCauley, S. R., Boake, C. M., Levin, H. S., Contant, C. F., & Song, J. X. (2001). Postconcussional disorder following mild to moderate traumatic brain injury: Anxiety, depression, and social support as risk factors and comorbidities. *Journal of Clinical Experimental Neuropsychology*, 23(6), 792-808.

Maxwell, S. (2012). *Big boss brain*. Bowie, MD: 4TH Division Press, an imprint of E. L. Kurdyla Publishing LLC

Maxwell, S. (2011). *My daddy is invincible*. Bowie, MD: 4<sup>TH</sup> Division Press, an imprint of E. L. Kurdyla Publishing LLC

Sjolinder, P. (2014). Case Series: The Effects of Chronic mTBI Symptoms: The Caregiver's Perspective.

Unpublished raw data.

U. S. Department of Veterans Affairs, U. S. Department of Defense. (2009). *VA/DoD clinical practice guideline for management of concussion/mild traumatic brain injury*. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed/2010844>

Wenger, G., Davies, R., Shahtahmasebi, S., & Scott, A. (2008). Social isolation and loneliness in old age: Review and model refinement. *Aging and Society, 16*, 333- 358.

doi: 10.1017/S0144686X00003457

Zayfert, C. & DeViva, J. C. ( 2011). When someone you love suffers from posttraumatic stress. New

York, NY: Guilford Press

# Questions?

- Submit questions via the Q&A box located on the screen.
- The Q&A box is monitored and questions will be forwarded to our presenters for response.
- We will respond to as many questions as time permits.





# A HEAD FOR THE FUTURE

A Head for the Future, an initiative of the the Defense and Veterans Brain Injury Center, raises awareness of the signs, symptoms and treatment of TBI.

**Prevent** Protect Your Head

**Recognize** Know the Signs & Symptoms

**Recover** Get Checked Out & Rest

Visit [dvbic.dcoe.mil/aheadforthefuture](http://dvbic.dcoe.mil/aheadforthefuture) to learn more about TBI and discover educational resources.

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@AHFTF\_Page



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4. Verify, correct, or add your information AND Select your profession(s).
5. Proceed and complete the activity evaluation
6. Upon completing the evaluation you can print your CE Certificate. You may also e-mail your CE Certificate. Your CE record will also be stored here for later retrieval.
7. The website is open for completing your evaluation for 14 days.
8. After the website has closed, you can come back to the site at any time to print your certificate, but you will not be able to add any evaluations.

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# Save the Date

**Next DCoE Psychological Health Webinar:  
Pharmacology in the Treatment of Behavioral Health Conditions  
October 29, 2015; 1-2:30 p.m. (ET)**

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**Next DCoE Traumatic Brain Injury Webinar:  
ICD-10 Coding for Traumatic Brain Injury  
November – To Be Announced**

# DCoE Contact Info

**DCoE Outreach Center**  
**866-966-1020 (toll-free)**

**dcoe.mil**

**resources@dcoeoutreach.org**