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For Psychological Health
& Traumatic Brain Injury

Today's webinar:

Family Caregiver Support After Traumatic Brain Injury

April 10, 2014, 1-2:30 p.m. (EDT)

Presenter:

Janet Cromer, R.N., M.A., BCPC

Moderator:

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Contract support to the Defense and Veterans Brain Injury Center

Silver Spring, Md.



Webinar Details

- Live closed captioning is available through Federal Relay Conference Captioning (see the “Closed Captioning” box)
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 - Dial: CONUS **888-877-0398**; International **210-234-5878**
 - Use participant pass code: **3938468**
- Question-and-answer (Q&A) session
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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

The screenshot displays the Adobe Connect interface for a webinar titled "DCoE TBI January 2014 Webinar". 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.

At the bottom of the main content area, there are logos for DWBIC, DHCC, and a third organization. A red circle highlights the "Files for Download" section in the left sidebar, which contains the following table:

Name	Size
Back to School Guide to Academic Suc	1 MB
Neuroimaging Following mTBI Clinical	313 KB
Neuroendocrine Dysfunction Screening	268 KB
Diagnosis Associated with mTBI Refere	302 KB

Below the table is a "Save To My Computer" button. The "Web Links" section below it lists "D CoE Website", "DV BIC Website", and "DHCC Website". At the bottom of the sidebar, there is a "Browse To" field with the URL <https://ice.disa.mil/index.cfm?fa=c>.

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.
 - Currently, only those contractors with scope of work or with commensurate contract language are permitted in this training.
- All who registered **prior** to the deadline on **Thursday, April 10, 2014**, at 3 p.m. (EDT) and meet eligibility requirements stated above, are eligible to receive a certificate of attendance or CE credit.

Continuing Education Details (continued)

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Continuing Education Details (continued)

- Credit Designation – The Duke University School of Medicine designates this live webinar for:
 - 1.5 AMA PRA Category 1 Credit(s)
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 - 1.5 ANCC nursing contact hours
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Continuing Education Details (continued)

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Webinar Overview

- Family caregivers require and benefit from specialized support, education and understanding from health care professionals as they move through stages of adaptation that often correspond with the treatment and recovery of a service member who sustained a traumatic brain injury (TBI).
- In 2010, the Defense and Veterans Brain Injury Center (DVBIC), in collaboration with the Defense Health Board, developed a “Guide for Caregivers of Service Members and Veterans.” This guide contains four modules that provide in-depth information for family caregivers of service members or veterans who sustained a moderate to severe or penetrating TBI. This includes information to help family caregivers understand TBI, how to advocate, help children cope with TBI and how to navigate services and benefits.
- This webinar will review common emotional and cognitive responses, caregiver responsibilities, learning needs and educational interventions. This discussion will explore how to build a therapeutic alliance with families and resources for professionals to enhance their understanding of the family caregiver’s experience and perspective.

Webinar Overview

- At the conclusion of this webinar, participants will be able to:
 - Illustrate common emotional responses and role responsibilities of family caregivers during the acute and rehabilitation stages
 - Identify signs and symptoms of secondary traumatic stress in family caregivers
 - Educate family caregivers about two self-regulation techniques to enhance parasympathetic nervous system function
 - Construct effective skill building strategies to educate, empower and encourage family caregivers during the crisis and rehabilitation stage

Presenter: Janet Cromer, R.N., M.A., BCPC



Janet Cromer

- Medical and psychiatric registered nurse with extensive experience in clinical, leadership and educator positions
- Licensed psychotherapist, specializing in psychological aspects of medical illness, stress and trauma resilience, mind-body health, and creativity and healing
- Author of “Professor Cromer Learns to Read: A Couple’s New Life after Brain Injury”
- Involved in the brain injury community since 1998 as a psychotherapist, support group facilitator, educator and advisory board member
- National speaker on stress resilience, compassion fatigue, and health care professional and family caregiver mental health
- Holds an M.A. from Lesley University Graduate School, Division of Counseling Psychology and Expressive Arts Therapies. Registered Art Therapist, Board Certified Professional Counselor, Certified Compassion Fatigue Educator



Family Caregiver Support after Traumatic Brain Injury (TBI)

Janet Cromer, R.N., M.A., BCPC

Disclosure

- The views expressed in this presentation are my own and do not reflect the official policy of the Defense Department or U.S. Government.
- I have no relevant financial relationships to disclose.
- I do not intend to discuss the off-label/investigative (unapproved) use of commercial products or devices.

Why Do Family Caregivers (FCGs) Matter?

Caregivers of Veterans – Serving on the Homefront

Study conducted by the National Alliance for Caregiving and funded by United Health Foundation – November, 2010

- 462 FCGs, injury or illness related to military service from World War II to Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF)
- Key findings: 96% women; 70% care for spouse/partner except 26% of OEF and OIF veterans cared for by parents
- 30% provided care for ten or more years
- 65% in high-burden situation; 80% say veteran has two or more specific conditions
- 68% consider situation highly stressful

(United Health Foundation, 2010)

Caregivers of Veterans – Serving on the Homefront

- 40% have high degree of physical strain
- 47% stopped work or took early retirement
- 30% have children under 18; 70% of them spend less time with children than would like
- 57% report children or grandchildren have emotional/school problems as result of their caregiving or veteran's condition
- 75% say caregiving or veteran's condition placed strain on marriage
- 88% feel increased stress or anxiety, and 77% report sleep deprivation
- Majority report decline in own health habits
- Caregivers are overwhelmingly proud of service they provide

(United Health Foundation, 2010)

Additional Family Considerations

Current Caregivers

- Move to be with service member, leave support network, or long-distance caregiving
- Disagreements between generations, role conflicts
- Stage of family life cycle, premature caregiver/change in roles, duration of marriage, young children
- Meaning of injury, co-occurring conditions
- Loss of job, career, financial pressures
- Relationship and intimacy issues

Family Problems Caused by TBI

- Chronic stress
- Inadequate interpersonal functioning
- Untimeliness of injury
- Lack of information
- Negative sick role expectations
- Social isolation
- Lingering grief
- Sexual concerns

(Dell Orto & Power, 1997, p. 61)

Polling Questions

What percentage of time is a family caregiver present for your interaction with the service member/veteran in your current work setting?

- A. 0-25%
- B. 26-50%
- C. 51-75%
- D. 76-100%
- E. N/A

Are educational programs for family caregivers offered at your work location?

- A. Yes
- B. No
- C. I'm not sure.
- D. N/A

Is mental health counseling for family caregivers offered at your work location?

- A. Yes
- B. No
- C. I'm not sure.
- D. N/A

Building a Therapeutic Partnership

Goals:

- Ensure best treatment for wounded service member. Better emotional functioning in caregivers was associated with greater occupational and social integration outcomes for persons who entered the post-acute rehabilitation program within six months of injury.
- Begin to facilitate healthy adaptation, resilience and post-traumatic growth for service member, family caregiver and family.

(Sander, Maestas, Sherer, Malec, & Natakase-Richardson, 2012)

Building a Therapeutic Partnership

Tips:

- Do not make assumptions about the nature of the relationship before injury and now. Ask, don't judge. "Careful re: 'loved one'."
- Provide information on team, roles, responsibilities and try to assign semi-consistent communicator.
- Provide information on team's expectations of caregiver (CG), resources, self-care strategies and ombudsman program.
- Assist CG to assess own critical needs, strengths, supports and learning needs.
- To increase empathy and understanding, invite caregivers to speak at conferences, Grand Rounds, etc. Read CG blogs and books.
- Avoid the "take care of yourself" trap!

Building a Therapeutic Partnership

High-yield questions to ask at intervals:

- How are you?
 - Touch arm and make eye contact.
- Can you tell me about your relationship at the time of the injury? Now?
- How are you feeling about being his caregiver?
- What is the hardest part of this for you right now?
- What other stressors do you have that would be helpful for us to understand? What else would you like us to know about you?
- What is your biggest hope? Most immediate goal for the service member?

Overview of Stages/ Seasons of Caregiver Adaptation

Each stage has key challenges, emotional responses and learning needs:

1. Crisis stage
2. Rehabilitation stage
3. Transition Home/"New Normal" stage
4. Long-term Care stage

Stage 1 – Crisis

Time:

- Injury to early rehabilitation

Key Challenges:

- Comprehend medical information
- Make critical decisions and plans
- Form trusting alliances
- Learn to triage
- Start to learn to take control in healthy ways
- Practice basic self-care
- Start to be case manager for service member and family

Stage 1 – Crisis

Emotional Responses:

- Shock
- Loss of control
- Denial
- Global hope
- Grief
- Anxiety
- Anger
- Confusion
- Guilt
- Exhaustion
- Heroic effort
- “Run on adrenaline”
- Relief
- Depression
- Potential acute traumatic stress response

Secondary Post-traumatic Stress (PTS) Response in Caregivers

- Study on PTS symptoms in relatives in first few weeks after severe TBI: More than 50% had clinically significant PTS symptoms after relative's accident.
- More severe symptoms in women and relatives of patient with poorer Glasgow Coma Scale scores.
- Assess impact since it may interfere with ability to be involved in decisions. Initial mental health problems should be assessed and treated, may complicate long-term adjustment.
- May be under-recognized and under-reported, contribute to anxiety, depression, grieving, sleep disorders, poor functioning.

Stage 1 – Crisis Interventions

- Screen caregiver for mental health issues, traumatic stress response.
- Be aware that information might not be retained. Repeat, give handouts, multimedia resources. Involve support person in decision making.
- Introduce skills to begin to regain control: problem solving, organizing information, specific resources. Encourage to focus on this moment, this day.
- Introduce basic mind-body self-regulation skills: diaphragmatic breathing, progressive muscle relaxation, meditation. Model in meetings, have CDs and handouts available on unit. Give permission. Lay foundation for future.

Stage 1 – Crisis Interventions

- Discuss and give material on secondary PTS reaction and disorder. Acute response may occur early but can become chronic if not treated.
- Teach to recognize signs/symptoms related to reliving event including nightmares, flashbacks, intrusive memories.
- Signs/symptoms of hyperarousal include hypervigilance, anxiety, irritability, trouble sleeping.
- Also include avoidance symptoms such as numbing, apathy, avoiding places and activities, memory and concentration problems and withdrawal.

Stage 1 – Crisis Interventions

- Refer for treatment.
- As inscribed on the wall of the National Intrepid Center of Excellence on the grounds of the Walter Reed National Military Medical Center:

**“Reduce suffering, instill hope and
address moral injury.”**

- Please extend to caregivers.

Stage 2 – Rehabilitation

Time:

- Early rehabilitation to discharge home

Key Challenges:

- Understand changes and meaning
- Shape expectations/hope in time of uncertainty
- Partner with team, participate in care and treatment, identify strengths and resources wanted
- Manage all other areas of family life and work
- Practice more consistent stress resilience plan
- Learn to carry over all rehabilitation professional roles for discharge

Stage 2 – Rehabilitation

Emotional Responses:

- Depression
- Ambiguous loss (“stranger syndrome”)
- Grief
- Anxiety
- Anger, resentment
- Ambivalence
- “Reality slams”
- Potential post-traumatic response
- Pride, satisfaction with participation
- Emotions can seem contradictory and unstable

Chronic Sorrow and Ambiguous Loss

Chronic sorrow is characterized by:

- Non-pathological set of recurrent grief responses resulting from a significant loss or absence of crucial aspects of oneself or another person. Painful discrepancy between what is perceived as reality and what continues to be dreamed of. Source of loss continues to be present. (Roos, 2002).
- Per Boss (2006), the most stressful kind of loss is due to ambiguity.
 - Type 1. Person is physically absent but psychologically present.
 - Type 2. Person is physically present but psychologically absent due to being emotionally or cognitively missing.
 - Guidelines for treatment of the family include finding meaning, tempering mastery, reconstructing identity, normalizing ambivalence, revising attachment and discovering hope.

Stage 2 – Rehabilitation Interventions

- Listen to ambivalence and fear, normalize if appropriate. Point out examples of ambiguous loss.
- Suggest new outlets for new emotions. Try counseling, support group, visual journaling, movement, exercise, mindfulness, spiritual practices.
- Introduce to “realistically resilient” role model. Having a resilient role model is one of ten resilience factors. (Southwick & Charney, 2012).
- Provide detailed resource materials for all treatments, routines, medications. Provide applications for self-care, resource websites. Pick key concepts to reinforce.

Stage 3 – Transition Home/“New Normal”

Time:

- Discharge from hospital/rehabilitation going forward

Key Challenges:

- Updating family roles and routines
- Continuing rehabilitation and treatments
- Mobilizing ongoing supports
- Managing “red tape” of administrative responsibilities
- Financial issues
- Independence vs. dependence
- Community integration
- Preventing exhaustion, burnout and compassion fatigue

Stage 3 – Transition Home/“New Normal”

Emotional Responses:

- Insecurity without staff availability
- Fear
- Gratitude
- Depression
- Worry
- Anger
- Exhaustion
- Isolation
- Increasing confidence

Stage 3 – Transition Home/“New Normal” Interventions

- Provide emergency plan for psychiatric and medical emergencies.
- Discuss consistent stress resilience plan. Teach CG any strategies/techniques service member will utilize for posttraumatic stress disorder (PTSD), depression, anger, etc. Emphasize importance of respite.
- Include civilian support organizations in resource packet.
- Educate regarding depression signs/symptoms and treatment resources. Caregivers keep functioning so depression is under-diagnosed.
- Educate regarding burnout and compassion fatigue. Give list of signs/symptoms, prevention strategies.

Caregivers of Veterans – Serving on the Homefront Recommendations

- Provide training and information for common conditions. Create condition-specific CG info and training. Offer toll-free 24-hour line with support, information, referrals.
- Help caregivers help one another. Develop central website for CG support groups, forums, blogs. Establish CG peer mentoring program.
- Teach CG about resources available. Ensure CG receives directory of Department of Veterans Affairs and other governmental and community programs and services. Teach CG about advocacy resources and methods. Create list of financial assistance for range of needs. Direct CG to legal assistance. Facilitate searches for specialized care facilities.

Caregivers of Veterans – Serving on the Homefront Recommendations

- Help CG find respite and relief.
- Improve dissemination of existing resources specifically for CG.
- Sensitize health care providers to CG's role. Include in treatment decisions. Show how to administer medications and treatments. Empower care managers to provide services for CG themselves.
- Provide other information and tools. Help plan for veteran's transitions. Explain veteran's conditions to family members.

References

- Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. NY: W.W. Norton.
- Dell Orto, A., & Power, P. (1997). *Head injury and the family: A life and living perspective*. Boca Raton, FL: GR/St. Lucie Press.
- Department of Veterans Affairs & Department of Defense. (2010). VA/DoD clinical practice guideline for management of post-traumatic stress (version 2.0). Retrieved from http://www.healthquality.va.gov/guidelines/MH/ptsd/cpg_PTSD-FULL-201011612.pdf
- National Alliance for Caregiving & United Health Foundation. (2010). Caregivers of veterans – Serving on the homefront. Report of study findings. Retrieved from <https://www.unitedhealthfoundation.org/uhfassets/docs/2010/caregivers-of-veterans-study.pdf>
- Pielmaier, L., Walder, B., Rebetz, M., & Maercker, A. (2011). Post-traumatic stress symptoms in relatives in the first weeks after severe traumatic brain injury. *Brain Injury*, 25(3), 259-265.
- Post-traumatic stress disorder. (2013). In *A.D.A.M. Medical Encyclopedia*. Retrieved March 19, 2014, from U.S. National Library of Medicine: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001923>
- Roos, S. (2002). *Chronic sorrow: A living loss*. NY: Brunner-Routledge.
- Sander, A., Maestas, K., Sherer, M., Malec, J., & Natakase-Richardson, R. (2012). Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, 93(5), 842-848.
- Southwick, S. & Charney, D. (2012). *Resilience: The science of mastering life's greatest challenges*. Cambridge, UK: Cambridge University Press.

TBI Recovery Support Program

(formerly known as Care Coordination Program)

Mission: To optimize successful engagement, treatment and recovery from traumatic brain injury (TBI) by providing TBI expertise, resources and support to the military and veterans' communities, and facilitating connections across the entire continuum of recovery and spectrum of care

Eligibility: Service members (including National Guard/reservists) or veterans who have sustained a TBI, family members or caregivers

Client Services: Support, education, advocacy and connection to TBI services and other resources for clients as they negotiate and transition through complex systems of care



For referrals and more information: info@dvbic.org

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

Tools that provide information and support for caregivers of service members and veterans with moderate to severe traumatic brain injury



Caregiver's
Companion

dvbic.dcoe.mil/family-caregiver-curriculum

Addressing Family Needs



Provides tips and guidance regarding care of a service member or veteran with a traumatic brain injury (TBI)

Booklet highlights:

- Building stronger family ties
- Improving communication
- Transitioning home
- Driving after a TBI
- Avoiding substance abuse

dvbic.dcoe.mil/material/addressing-family-needs

FAMILIES

Taking Care of Yourself While Caring for Others



Provides coping techniques for managing stress, anxiety or sadness; includes links for additional interviews

Includes tips regarding:

- Emotional health
- Sleep
- Diet
- Exercise
- Strategies for self-care

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 presenter for response.
- We will respond to as many questions as time permits.



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Save the Date

Next DCoE Psychological Health Webinar: *Psychological Health and Resilience of Children in Military Families*

April 24, 2014

1-2:30 p.m. (EDT)



Next DCoE TBI Webinar: *Post-traumatic Headache*

May 8, 2014

1-2:30 p.m. (EDT)



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