



# Respite for Heroes at Home

**Elevate Respite: National Lifespan Respite Conference**

**September 2016**

**Denver, CO**

Jed Johnson, Easterseals headquarters

Jennifer Dexter, Easterseals headquarters

Shannon Tuimalealiifano, Elizabeth Dole Fellow

# Agenda

- Welcome & Introductions
- Dole Caregiver Fellow
- Statistics, similarities & differences military and civilian caregivers
- Respite provider training supporting military caregivers
- Policy landscape and action steps
- Resources
- Micro-grants for Lifespan Respite Coalitions

# Learning Objectives

- Participants will:
  - Understand the history of Easterseals and their work in supporting service members/veterans and their families
  - Be able to identify the unique circumstances of military caregivers in comparison to their civilian counterparts
  - Increase knowledge related to providing respite support for service members/veterans and their families
  - Learn about 5 specialized modules of training for respite providers supporting military caregivers
  - Be aware of current policy landscape impacting military caregivers
  - Be able to identify at least 3 new resources related to the delivery of respite services supporting

# About Easterseals

- Established in 1919
- Largest health charity in US, with 550+ service sites
  - 74 U.S. Affiliates with partners in Puerto Rico, Canada, Mexico and Australia
- Headquarters – Chicago with Office of Public Affairs in DC
- Premier nonprofit provider of services for people with disabilities and other special needs and their families, working to create a world of inclusion, empowerment and independence.
- Support individuals with all disabilities across the lifespan with expertise in:
  - Caregivers across the lifespan
  - Young children, Autism, Youth transitioning from school to work
  - Adults & seniors
  - Mobility/transportation
- Supporting service members, Veterans & their families since WWII



# Military Caregiver Services/Supports

- Military Caregiver webinar series
  - October 20<sup>th</sup> & November 17<sup>th</sup>
  - [www.easterseals.com/carewebinar](http://www.easterseals.com/carewebinar)
- Exceptional Family Member Program
- National Veteran Caregiver Training Program
  - Contract with Dept. of Veterans Affairs to provide multi-modal training (35,000+ Veteran Caregivers)
- Elizabeth Dole Foundation Coalition for Military Caregivers (Respite Impact Council)  
[www.easterseals.com/militarycaregiver](http://www.easterseals.com/militarycaregiver)



**Coast Guard**



**Air Force**



**Navy**



**Marines**



**Army**

**“When one  
member joins  
the military,  
the whole  
family serves”**



# Shannon Tuimalealiifano

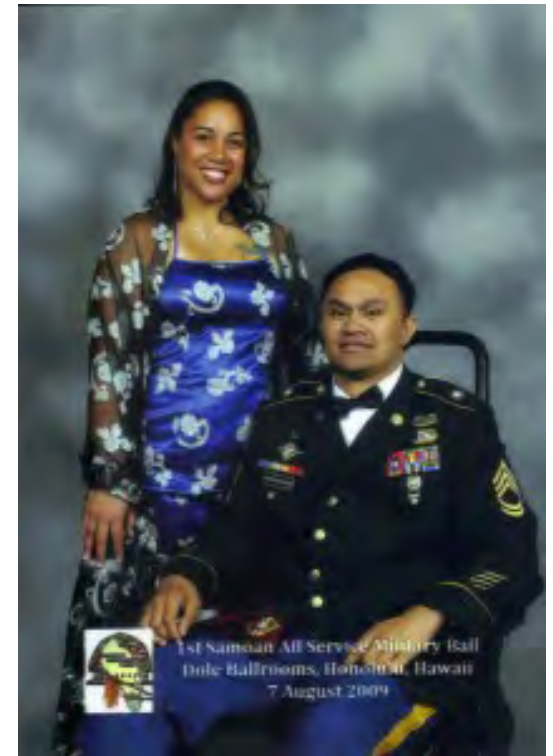
## Elizabeth Dole Fellow

Shannon is dedicated to helping other caregivers find the help that she did, through building connections with peers who truly understand because of their own “lived experience” with traumatic life changes. She knows the difference that peer support can make in one’s ability to cope with the many day-to-day challenges that caregivers face, including balancing other important roles as children, spouses, parents, mentors and advocates.

Shannon applies her personal experience and her educational background (A.S. in Health Sciences, B.S. in Human Services, M.A. in Biblical Wisdom) to all that she does on behalf of the military wounded, ill, and injured community who she considers not simply her passion, but also her family.

Shannon is the Elizabeth Dole Foundation Fellow for Florida (formerly for Hawaii) and is Peer Mentor Coordinator for TAPS.

Shannon is the daughter of two Vietnam-era veterans and served almost 10 years in the Army (three of those years as an Activated Reservist, post-9/11). A mother of three, her caregiving experience began during the extensive cancer treatment for her oldest child. She now serves as caregiver for her husband, a Special Operations soldier who returned from Afghanistan quadriplegic, with traumatic brain injury and post-traumatic stress that require extensive medical support.



# Hidden Heroes

## America's Military Caregivers

Rajeev Ramchand, Terri Tanielian,  
Michael P. Fisher, Christine Anne Vaughan, Thomas E. Trail,  
Caroline Epley, Phoenix Voorhies, Michael William Robbins,  
Eric Robinson, Bonnie Ghosh-Dastidar



## Key facts and statistics from the **RAND Military Caregivers Study**

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**9% of U.S. adults are caregivers**

**16.9 million**  
civilian caregivers

**4.4 million**  
Pre-9/11 military caregivers

**1.1 million**  
Post-9/11 military caregivers

Source: National survey of caregivers of adults in the U.S., with findings presented in Ramchand R, Tanielian T, et al., *Hidden Heroes: America's Military Caregivers*, RAND Corporation, 2014 (available at [www.rand.org/military-caregivers](http://www.rand.org/military-caregivers)).



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CAREGIVERS GIVING CARE  
TO PEOPLE WHO SERVED  
**pre-9/11**

r from

CAREGIVERS GIVING CARE  
TO PEOPLE WHO SERVED  
**post-9/11**

RECIPIENTS

RECIPIENTS



 Pre-9/11

 Civilian



OF THOSE



0%

Post-9/11

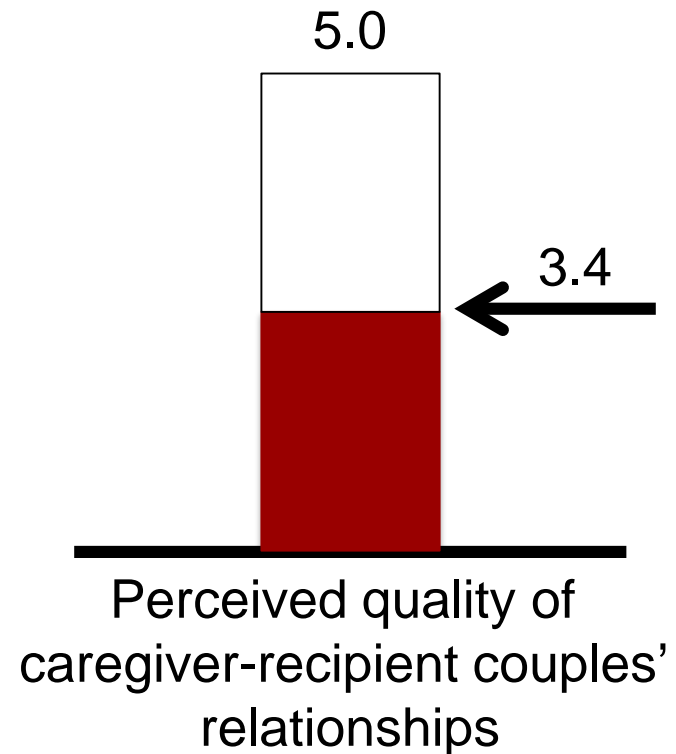
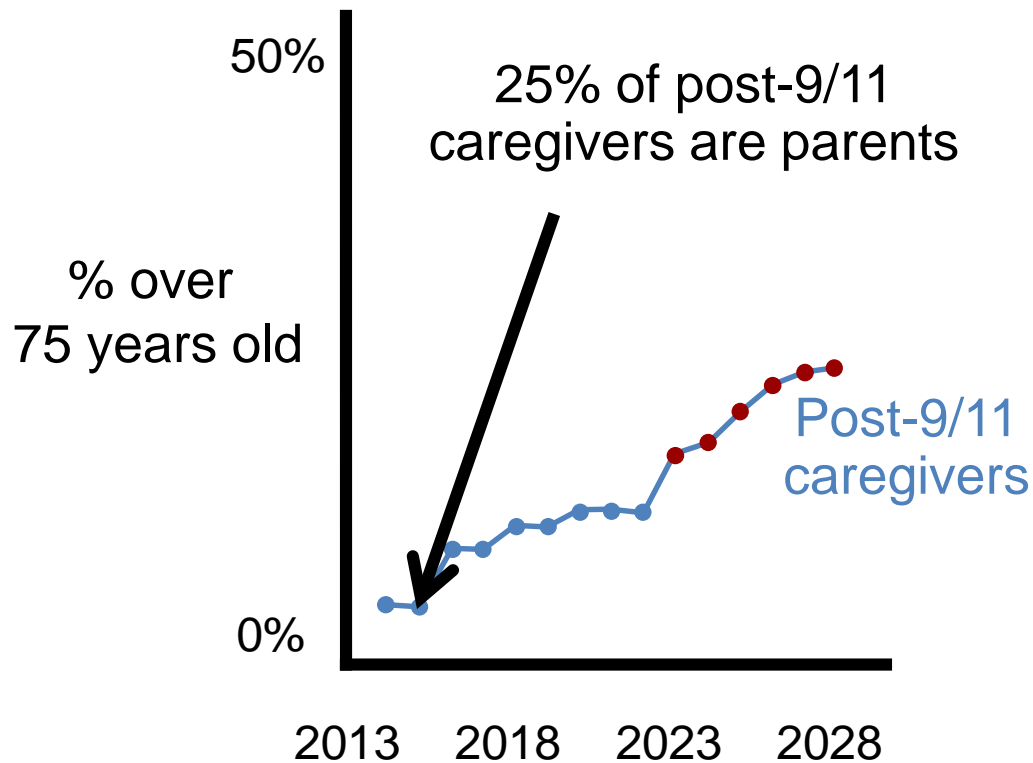
Pre-9/11

Civilian

% receiving mental  
health treatment



# Threats to the future of caregiving: aging parents and young marriages



# Respite Providers

## Supporting Military Caregivers

- Recognize, value and validate military culture
  - Hire service members, veterans and their families
- Know key military values and beliefs
- Diversity of Veterans and their experiences
- Prevalence of specific physical & behavioral health concerns
- Develop partnerships/collaborations

# Hidden Heroes Respite Provider Training

- Elizabeth Dole Foundation Respite Impact Council & other key partners
- 5 Training modules
  - Participant guide
  - PowerPoint slide deck
  - Respite scenario
  - Knowledge check
  - Additional Resources

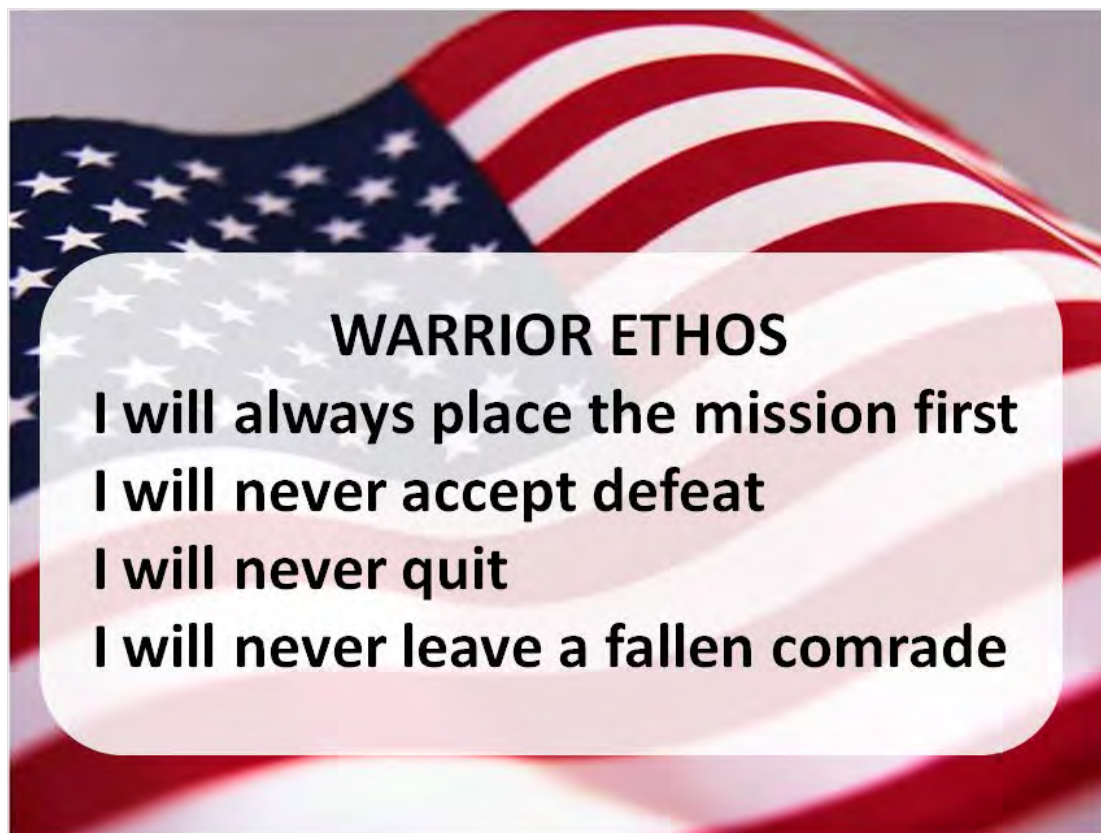


# Hidden Heroes Respite Provider Training

- About Military Caregivers
- Introduction to Military Culture
- Physical and Mental Health Concerns
  - Amputation, Burn Injuries, Hearing Loss, and Chronic Pain
  - Traumatic Brain Injury, Posttraumatic Stress, and Memory Loss
  - Depression, Substance Abuse and Suicide Prevention
- Home Life and Family Issues
- Respite Provider/Military Caregiver Relationship

# Respite Provider (sample discussion exercise)

- How might these core values impact Military caregivers:
  - Reaching out for respite support?
  - Your relationship with the caregiver?
  - With the veteran?



# Respite Scenario

Jun was in Iraq when the truck he was in hit an IED and blew up. He was blown out of the truck, receiving severe burns on his arms, chest, and part of his face. Airlifted to Landstuhl Army Regional Medical Center in Germany, he later spent significant time at the San Antonio Military Medical Center while having operations and skin grafts.

The scar tissue on his arms makes it difficult to reach all the way forward and even 2 years later, he still tires easily. Portions of his bottom lip had to be reconstructed, so sometimes his words aren't always clear when speaking.

He reports that, "People I meet sometimes have a hard time dealing with my burns. They try not to stare at my face and some seem uncomfortable when I extend my hand to shake theirs."

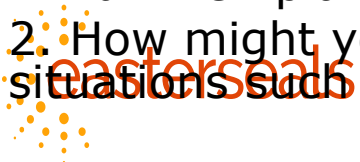
Jun studied to be a bookkeeper while he was healing and going through therapy. "After all, my brain still works great, it's just my body that isn't like it used to be," he says with a smile.

## Discussion Questions:

1. What factors might you and Jun want to keep in mind when planning activities?
2. How might you approach difficult public situations such as those described by Jun?



*JR Martinez: Veteran, actor, motivational speaker.  
Photo: Charles Edwards / Shutterstock.com*



# Differences based on era. . .

- » World War II (1939 – 1945)
- » Korean War (1950 – 1953)
- » Vietnam War (1961 – 1973)
- » Gulf War (1991)
- » Operation Enduring Freedom (Afghanistan) – (2001 – present)
- » Operation Iraqi Freedom (2003 – 2010)
- » Operation New Dawn (Iraq) – (2010 – present)

National Hospice and Palliative Care

Organization: [www.wehonorveterans.org](http://www.wehonorveterans.org)

Psycharmor: [www.psycharmor.org](http://www.psycharmor.org)

# Military Caregiver Public Policy Landscape

- Veterans Millennium Health Care and Benefits Act
- General Caregiving Trends
  - Respite
  - Financial Security through Tax Credits and Social Security Credits
- Hidden Heroes Caucus
- National Plan
  - RAISE Act
  - ACT Caucus

# Public Policy Action Steps

- Connect with Dole Fellows
- Invite Legislators to programs and events
- Communicate regularly with policy makers
- Sign up for action alerts at

<http://capwiz.com/easterseals/mlm/signup/>



# Resources & References

## VA Caregiver Support

- Additional information, and information supporting Veterans' families, and caregivers
- Caregiver Support Coordinators
- Toll-free Caregiver Support Line – 1-855-260-3274
- [www.caregiver.va.gov](http://www.caregiver.va.gov)

## National Military Family Association

- Programs that strengthen, and protect uniformed service families
- Children on the Homefront: The Experience of Children from Military Families
- [www.militaryfamily.org](http://www.militaryfamily.org)

# Resources & References

## Elizabeth Dole Foundation

- National Coalition for Military Caregivers
- Dole Caregiver Fellows Program
- Respite Impact Council tools & resources
- NEW [www.hiddenheroes.org](http://www.hiddenheroes.org)
- [www.elizabethdolefoundation.org](http://www.elizabethdolefoundation.org)

## Military Veteran Caregiver Network

- [www.milvetcaregivernetwork.org](http://www.milvetcaregivernetwork.org)

## Easterseals, Inc.

- Military Caregiver webinar series
- [www.easterseals.com/militarycaregiver](http://www.easterseals.com/militarycaregiver)
- National Veteran Caregiver Training Program

# Resources & References

## PsychArmor

- Providing free education and support on how to work with, live with, or care for military veterans.
- [www.psycharmor.org](http://www.psycharmor.org)
- Toll-free line "Helping You Help Veterans" Support Center at 844-PsychArmor

## RAND "Hidden Heroes" study and other resources

- The RAND Military Caregivers Study focuses on the caregivers of wounded, ill, and injured military servicemembers and veterans.
- [www.rand.org/military-caregivers](http://www.rand.org/military-caregivers)

# Resources & References

## U.S. Dept. of Agriculture Cooperative Extension System

- Military Families Learning Network webinars
- Other military caregiver resources
- [www.extension.org](http://www.extension.org)
  - (search “military caregivers”)
- eXtension – resource pages for Caregivers and Military Caregivers

## ARCH National Respite Network

- NEW Tools and Resources specific to military respite
- [www.archrespite.org](http://www.archrespite.org)

# Lifespan Respite Coalition Micro-grants

- \$500 each for up to 10 Coalitions
- Creative mechanisms to disseminate Hidden Heroes Respite Provider training
- Brief application
- Impact report
- To learn more:
  - Share contact info with Jed or Jennifer
  - Inquiries to [militarycaregiver@easterseals.com](mailto:militarycaregiver@easterseals.com)



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