

# The Changing Landscapes of Spousal Relationships Post Brain Injury

2014 AgrAbility National Training Workshop  
March 31-April 3, 2014



In 2014, we celebrate the 100<sup>th</sup> anniversary of the Smith-Lever Act, which created Cooperative Extension, the forerunner of modern-day MU Extension.

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**University of Missouri Extension**  
**MO AgrAbility Project**

# Session Objectives

- Describe spousal relationship changes in the post brain injury environment.
- Discuss Spousal caregiver “invisibility” and importance of caregiver support.
- Recommendations for spousal self-care and how professionals can help.

ONE DAY  
CAN BEND  
YOUR LIFE

MITCH ALBOM

# The Incident

- **Finding Out**
- **Shock – Disbelief**
- **Lack of Knowledge**
  - **Glasgow Coma Scale**
  - **Rancho Los Amigos Levels of Cognitive Function**
- **Advocacy**
- **Every Brain Injury Is Different as Is the Recovery**

# Brain Injury Definitions

## **Traumatic Brain Injury (TBI):**

- TBI is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force.
- Causes – Falls, Other, Motor vehicle, Struck by/against, Assault

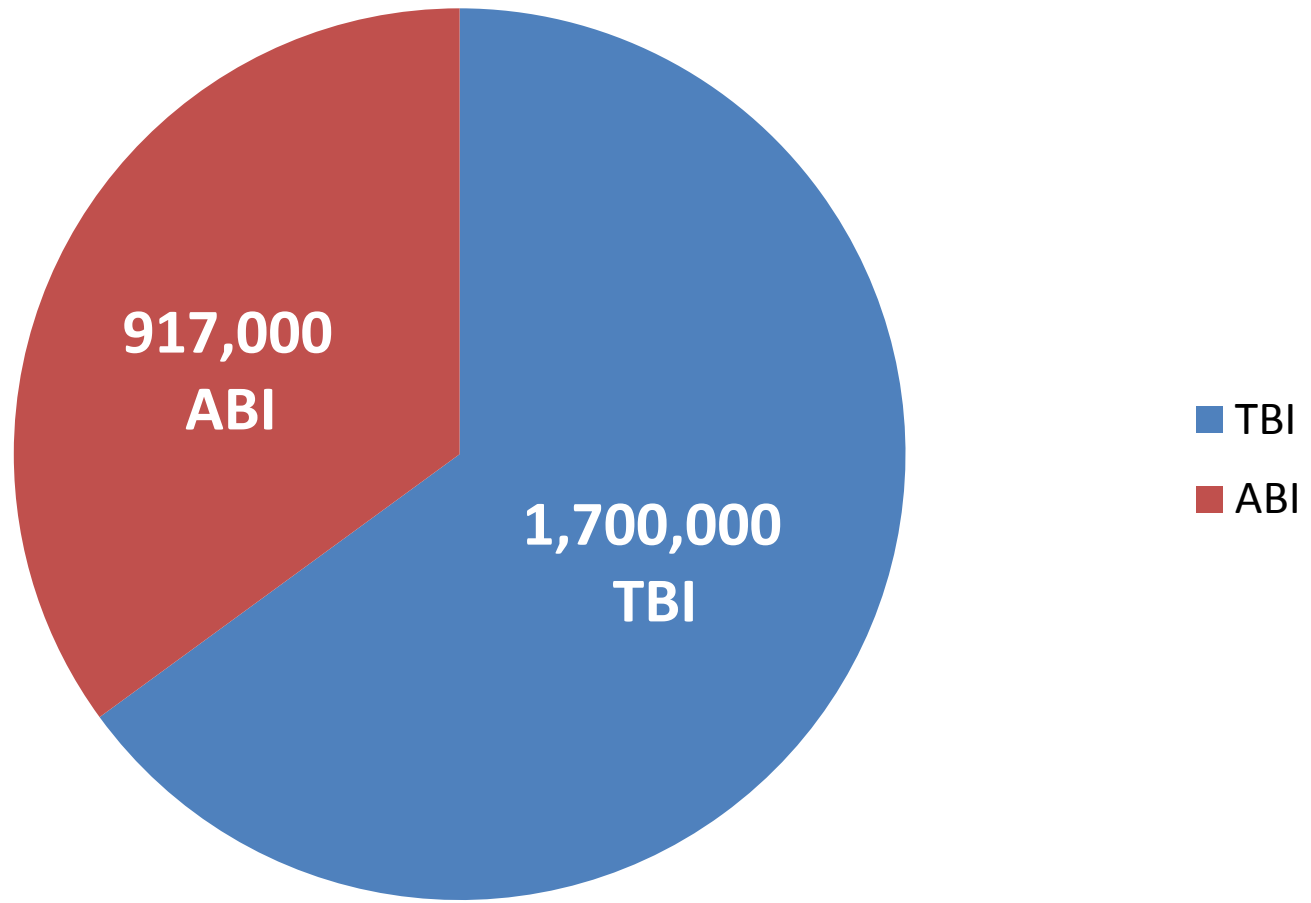
## **Acquired Brain Injury (ABI)**

- ABI is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth.
- Causes – Stroke Tumor, Aneurysm, Viral encephalitis, Multiple Sclerosis, Anoxic/hypoxic

# Brain Injury Statistics

- 5.3 million Americans live with a long-term disability as a result of TBI.
- Motor vehicle crashes and traffic-related incidences are the cause of 31.8% of TBI deaths.
- Males are more likely than females to sustain a TBI at any age.
- 75% of traumatic brain injuries are classified as “mild.”
- The annual cost of TBI to society exceeds \$76.5 billion.
- The estimated cost of stroke in the United States was \$53.9 billion in 2010.
- In 2005, nearly 1.1 million stroke survivors reported difficulty performing basic activities of daily life.

# Annual Incidence of TBI & ABI



# Consequences of TBI

- Neurological Impairment (motor, sensory, autonomic)
- Cognitive Impairment
- Personality and Behavioral Changes
- Common Lifestyle Consequences

Rehabilitation after Traumatic Brain Injury  
Khan, F.; Baguley, I.J.; & Cameron, I.C.  
Medical Journal of Australia Vol. 178  
March 2003 Pg. 290-295



# Caregiver Roles

- From Spouse and Partner
- To Caregiver and Reporter to concerned others
- Cheerleader
- Interpreter
- Decision Maker, bill payer, Dr. appointment, insurance sorter out, therapist (OT, PT, SL, etc.) and whatever else (kids, farm, household.....)
- Advocacy
- How is your spouse/partner doing? How are you doing?

# Slipping into Invisibility

- All that “stuff” on the last page
- Survivor may appear physically well and/or sound well - like their old self
- Needs for Safety, Prodding/Encouragement, Supervision
- What I should do?
- Where are my boundaries, my career, interest, friends.....?

# Stressors

- Survival of the “survivor”
- Role Changes
- Finances
- Career/education/business
- Fears – happen again, dementia, health issues
- Coming home .....
- .....with a stranger

# My spouse the stranger

- Behaviors – confusion and agitation
- Language barriers
- Therapy or Not
- Initial recovery vs. later recoveries
- Should I stay or Should I go?
- Support systems

# Recovery – Mine and Theirs

- What Can they do or not do – inside or outside the house (safety)
- Depending on level of Care needed – When can I leave them alone or taking them to care
- Returning to work or not
- Their self-awareness
- Calming my hyperalertness

**LIFE IS  
LIKE AN  
EVER  
SHIFTING  
KALEIDO  
SCOPE  
A SLIGHT  
CHANGE,  
AND ALL  
PATTERNS  
ALTER.**



**SHARON SALZBERG**

# Ambiguous Loss

“Boss (1999, 2004) coined the phrase ambiguous loss to describe grief and losses that leave survivors without closure or explanation. She argued that ambiguous loss occurs when a loved one is physically absent but psychologically present (that is, an abducted member) or physically present but psychologically absent (that is, a loved one with dementia).”

Webb, L.M. and Toller, P.W. (2014). Pg 179  
in *Stories of Complicated Grief: A Critical Anthology*

# Tough Questions

- I'm Married but don't have a husband/wife.
- Similar to "Alzheimer's widows/widowers"
- Dark thoughts
- Will I love this "new" person?
- How do I care for me?



**DON'T  
WORRY  
EVERYTHING  
IS GOING  
TO BE  
amazing.**

**UNKNOWN**

# Possible Hurdles

- Over hearing things are working
- Getting honest
- Relinquishing some responsibilities
- Unusual “therapies”
- Learning to Listen
- Learning to ask for what I need (including space)
- Appreciating the progress- accepting the frustrations

# Finding Your Way

- Learn as much as you can.
- Find a support system or create one.
- How do I get respite?
- What help do I need?
- What does self-care mean to me?
- What is my new normal?

# Questions?

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UNIVERSITY OF MISSOURI  
 **Extension**  
Live. And Learn.