

CAREGIVERS: OUR INNER STRENGTHS

***Get in Tune with Respite
October, 2014***

Pam Bryan and Jean Doster

CAREGIVERS: OUR INNER STRENGTHS

Brain Injury Basics

&

*BRAIN INJURY CAN HAPPEN TO ANYONE,
ANYTIME, ANYWHERE*

TOPICS

- **Introduction – My Family’s Story**
- **Brain injury basics**
- **What it means to be a caregiver**
- **Taking care of yourself (Evaluation Sheet)**
- **Understanding long term respite and benefits**
- **How to accept the help of respite providers**
- **Music and Humor – Vital to caregiver’s inner strengths**

The Bryan Family's Journey





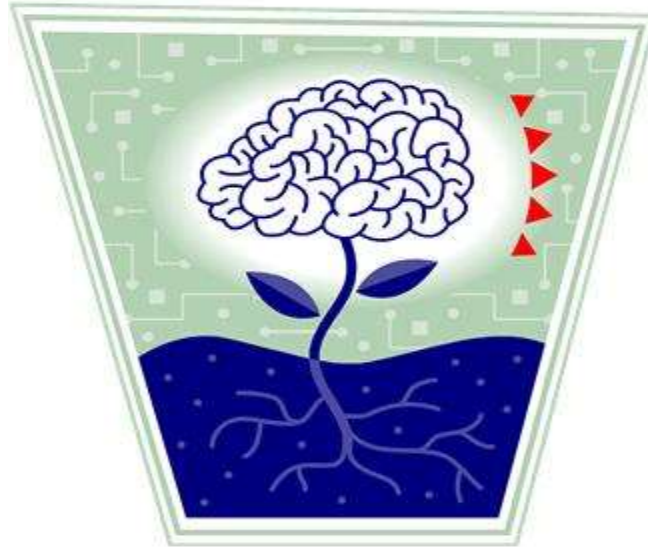
Five Weeks After Injury

Our Journey Continues

Our “New Normal”



Traumatic Brain Injury in Tennessee



“Brain Injury Basics”

Jean Doster, Director

Tennessee TBI Program

What is Traumatic Brain Injury?



What is Traumatic Brain Injury?

TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the function of the brain.

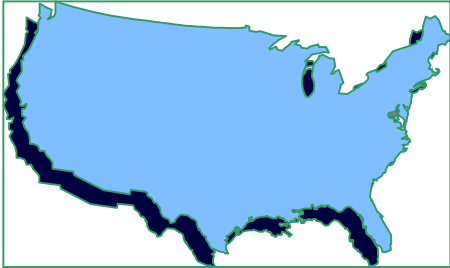
Not all blows or jolts to the head result in a TBI.

Is a concussion a traumatic brain injury?

Severity may range from mild to severe and can result in short or long-term problems.

The majority of TBIs that occur each year are mild.

TBI National Statistics

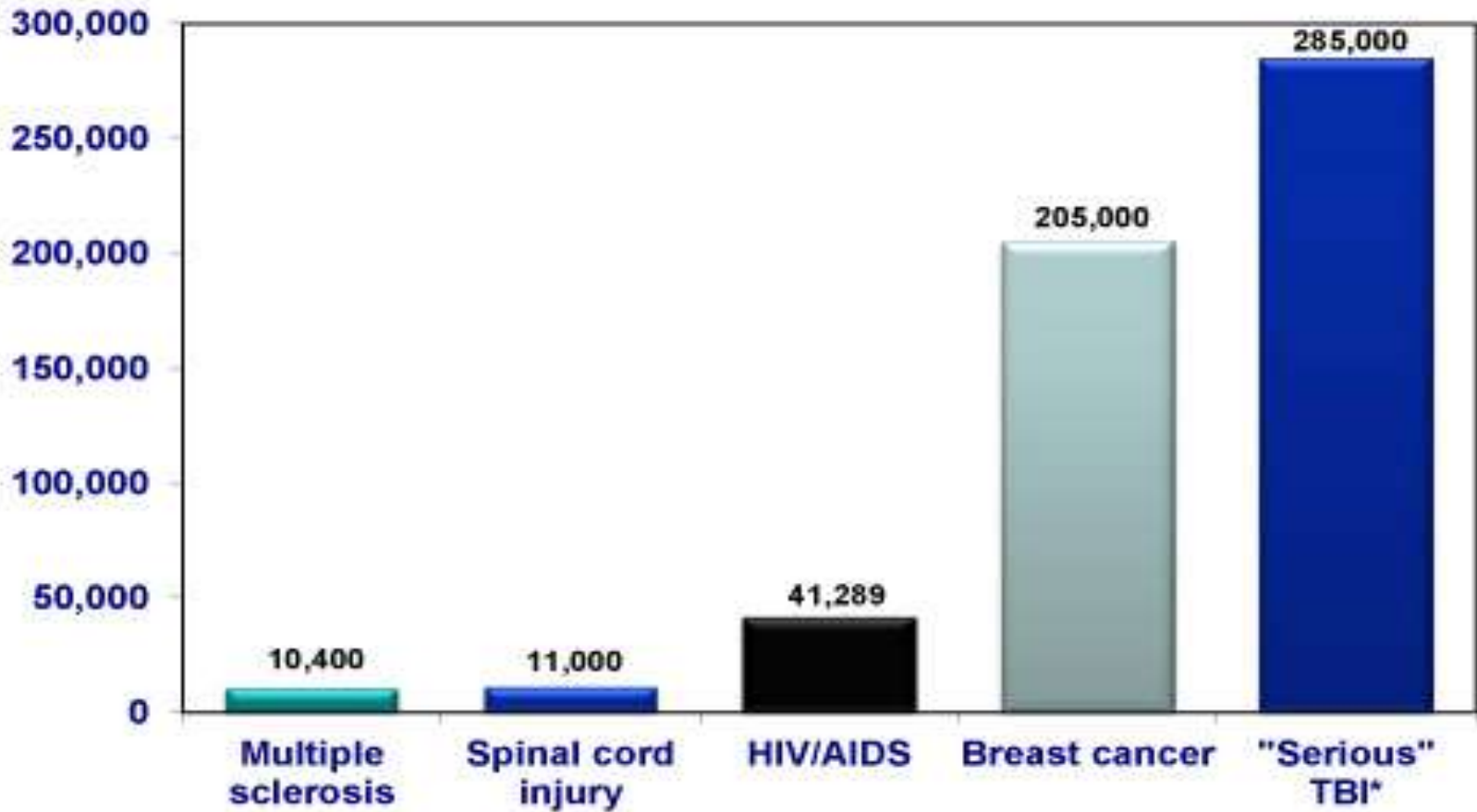


- Every year, 1.7 million people sustain a brain injury.
- Brain injury is the leading cause of death and disability among young children.
- An estimated 5.3 million Americans currently live with disabilities resulting from brain injury.

2.5 Million people sustain TBI

- Approximately 50,000 die
- 280,000 are hospitalized
- 2.2 million are treated and released from an emergency department

Comparison of new cases annually in the US

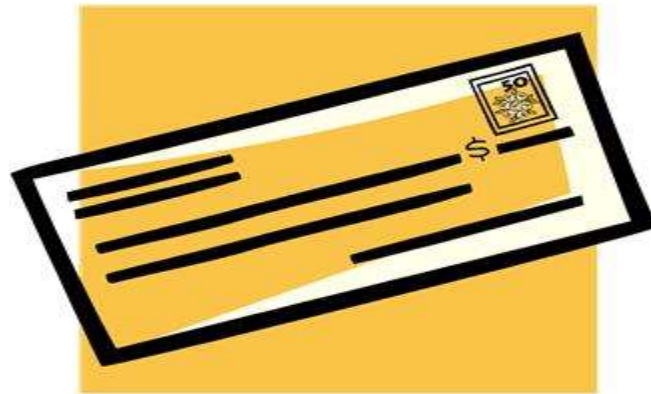


TN Brain Injury Registry

- In Tennessee, hospitals are mandated to provide information to the department on any person **admitted to the hospital** with particular codes for brain injury
- The Registry allows us to analyze the who, what, when and where of brain injury in the state.

Registry outreach

Any person included on the TBI registry receives a letter and program brochure which can connect them to needed services



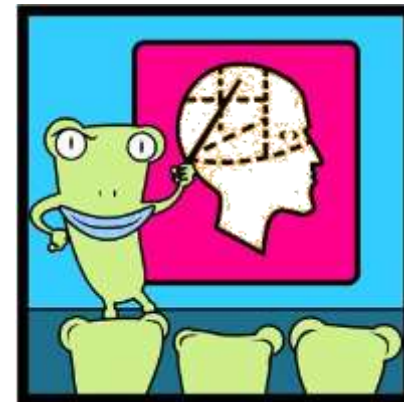
Brain Injury in Tennessee:

From Registry data, we know:

- Each year, approximately 8,000 people are admitted to the hospital.
- Each year, approximately 35,000 people enter the Emergency Room.
- Each year, approximately 220 people die.
- An estimated 100,000 Tennesseans currently have a long-term need for help due to a TBI.

Why haven't we heard about TBI before?

- Most people don't know about brain injury, let alone its consequences or how it affects people
- Most concussions do not involve loss of consciousness
- “Brain Injury is something you never think about until it becomes the only thing you think about.”



Leading Causes of TBI

Nationally

- 41% Falls
- 14% Motor vehicle traffic
- 15.5% Struck by / against events
- 11% Assaults

In Tennessee

- 52% Falls
- 24% Motor vehicle traffic
- 7.5% Homicide and other violent injuries
- 13% Other

Groups at risk for TBI

Anyone can sustain a brain injury. Some people have a higher risk.

- Males are about twice as likely as females to sustain a TBI.
- Age groups most impacted - adolescents, young adults, elderly.
- Adults age 75 years or older - highest rates of TBI-related hospitalization and death.

Things to know about TBI

- Every brain injury is different and the effects depend the cause, location, and severity
- Brain injury is unpredictable in its outcomes, and functioning may change and improve over time.
- The effects of a brain injury are complex and vary greatly from person to person

Consequences of TBI

- Traumatic Brain Injury consequences:
Physical, Emotional/behavioral, Cognitive
- Physical changes - more visible
- People with cognitive changes may be less aware of their limitations

Physical Changes

Common physical changes after brain injury:

- Pain – especially headache
- Impairment of body movement
- Speech and swallowing problems
- Fatigue and Sleep disturbances
- Spasticity
- Seizures



Physical, example

Motor coordination

Try this exercise:

1. Slightly lift your right foot off the floor
2. Begin circling that foot clockwise
3. Continue circling your foot while you write your whole name in cursive.

Emotional/Behavioral Changes

- Inability to control emotions
- Social inappropriateness
- Sexual inappropriateness
- Mood swings
- Lack of response to social cues
- Stress, anxiety, frustration



Cognitive Changes

- Memory impairments
- Slowed processing speed
- Attention deficits
- Language comprehension difficulties
- Sequencing difficulties
- Initiation problems



Cognitive, example

Processing speed

Quickly state the WORDS:

Pink

Blue

Red

Yellow

Black

Orange

Yellow

Processing speed

Now, quickly state the COLORS:

Pink

Blue

Red

Yellow

Black

Orange

Yellow

Traumatic Brain Injury Program

Tennessee Department of Health
Traumatic Brain Injury Program provides:

- **Information and referrals**
- **Service Coordination**
- **Camp**
- **TBI Registry**



Service Coordination

- **Eight service coordinators across Tennessee serve all 95 counties**
- **Services provided:**
 - **Provide information on TBI**
 - **Refer consumers to services**
 - **Assist consumers in applying for services**
 - **Support group development**



Resources

TN TBI Program

<http://health.tn.gov/TBI/index.htm>

1-800-882-0611

***Tennessee Traumatic Brain Injury Services Directory and
Resource Information Guide***



Resources, cont'd

- Websites for more TBI information:
Brain Injury Association of America
www.biausa.org
Brain Injury Association of Tennessee
www.braininjurytn.org
CDC
www.cdc.gov/traumaticbraininjury/



What It Means To Be A Caregiver

- **Emotional Support**
- **Listening**
- **Physical Care**
- **Transportation**
- **Advocacy**
- **Financial Assistance**
- **Companionship**

The highest reward for a person's toil is not what they get for it, but what they become by it.

John Ruskin

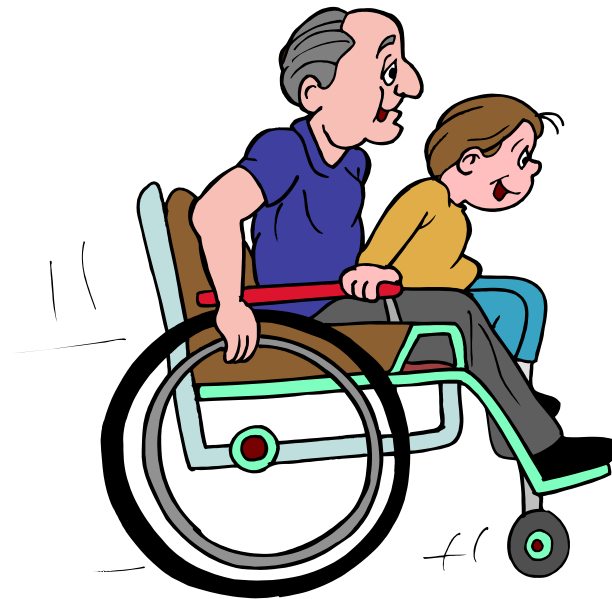
What it Means to be a Caregiver

- **Patience and Understanding**
- **It is normal to have many and mixed feelings**
- **Because each care receiver's situation is different, each person needs different assistance and support from a caregiver**

What it Means to be a Caregiver

Elements of a Caring Relationship

- Knowledge
- Patience
- Honesty
- Trust
- Humility
- Hope
- Courage



What it Means to be a Caregiver

Feelings Experienced by Caregivers

Negative

- **Fatigued/Tired**
- **Loss/Grief**
- **Stress/Depression**
- **Anger**
- **Loneliness**
- **Overwhelmed**



Positive

- **Rewarding**
- **Meaningful**
- **Self-Confidence**
- **Trust**
- **Advocate**
- **Sense of Pride**



*“Worrying is like a rocking chair...
It gives you something to do but doesn’t get you anywhere”
Tom Wilson as “Ziggy”*

What it Means to be a Caregiver

Impact on Family Members, Caregivers, and Supporters

- **Role Changes**
- **Relationship Changes**
- **Advocating for legal, medical, and community services**
- **Supplementing or solely providing family income**

Taking Care of Yourself



“The healthiest way to care for another is to care for yourself”

(James Miller, 1993)



Taking Care of Yourself

Consequences of not taking care of yourself

To be a caregiver you need the heart of a butterfly and the skin of a rhinoceros

- Sleep deprivation = exhaustion, fatigue
 - Poor eating habits
 - Failure to exercise
 - Postponing or failing to make medical appointments for yourself
 - Increased risk of depression
- (Just a few examples of possible effects of caregiving)*

Taking Care of Yourself

How can Stress Affect You

Some Signs of Stress

- High Blood Pressure
- Confusion
- Depression
- Heart Attack or Stroke
- Problems with work or relationships
- Mood Changes
- Headache
- Nervousness
- Fast heartbeat
- Tight Muscles

Control Stress – You'll See and Feel the Benefits

By managing stress, you can feel more:

- Refreshed – and have more energy
- In control – because you're calmer
- Alert – and focused on the day ahead



Taking Care of Yourself

What You can Change and Cannot Change

The challenge we face as caregivers is well expressed in words from the Serenity Prayer:

*...Grant me the serenity to
Accept things I cannot change,
Courage to change the things I can,
And the wisdom to know the difference*

Respite

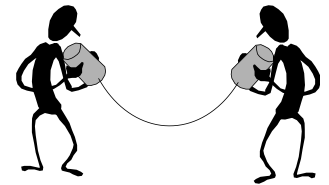
- **Respite care** is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. *Wikipedia, the free encyclopedia*
- Even though many families take great joy in providing care to their loved ones so that they can remain at home, the physical, emotional and financial consequences for the family caregiver can be overwhelming without some support, such as respite.

Respite Care

- Respite care provides short-term breaks that can relieve stress, restore energy, and promote balance in your life.
- Using respite care before you become exhausted, isolated, or overwhelmed is ideal, but just anticipating regular relief can become a lifesaver.
- Respite care can take many forms, but boils down to two basic ideas: sharing the responsibility for caregiving and getting support for yourself. Finding the right balance requires persistence, patience, and preparation.

BUILDING A COOPERATIVE RELATIONSHIP

➤ **Effective Communication**



➤ **Mutual Respect**



➤ **Trust**



SUGGESTIONS FOR DEVELOPING TRUST AND RESPECT

PROFESSIONAL



FAMILY

- ❖ Listen actively to the concerns and needs expressed by *family* caregivers
- ❖ Allow *family* caregivers expertise to shine

- ❖ Listen actively to information and concerns shared by *professional* caregivers
- ❖ Allow *professional* caregivers expertise to shine

Successful Respite Care

- **Plan and schedule frequent breaks.**
- **Use checklists to inform respite care providers about your care recipient's schedules, likes and dislikes.**
- **Make back-up plans.**
- **Evaluate respite care providers often. Observe your care recipient before and after respite sessions.**
- **Expect changes. Anticipating and accepting changes in personnel or programs can keep you from becoming discouraged.**
- **Attend your support group regularly.**

Role of Humor in Caregiving

- Laughter really is the best medicine
- Laughter releases tension, eases pain, improves your breathing, elevates your mood, and in general, improves your outlook on life
- Try to find humor in everyday life



Role of Music in Caregiving

Music can lift your mood when you have the blues. Music can make your heart soar.

Studies show listening to music can lead to increased secretion levels of melatonin, a hormone associated with mood regulation, lower aggression, reduced depression and enhanced sleep.

Using music to cope with stress can be a welcome relief to caregiver burn-out.



Caregivers are Very Special People!

“There are only four kinds of people in world – those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who need caregivers”

**--Former First Lady
Rosalyn Carter**



Thank You!

Questions:

Jean Doster

Director, State TBI Program

Pam Bryan

Family Caregiver

Alliance of Brain Injury Survivors and Family/Caregivers

Advocate

