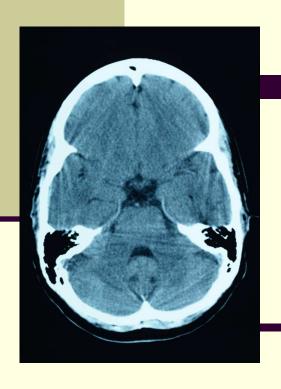
# The Graying of Brain Injury: Aging and Lifespan Issues



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# Brain Injury: A lifetime of disability

- A convergence between the disabilities acquired in the brain injury and the normal consequences of aging
- Creation of a more vulnerable population living with functional limitations and increased healthcare problems
- Increase in the need for physical assistance and specialized care over the course of time due to accelerated problems







- Age Based
- Mobility problems
- Functional loss
- Hearing and vision loss
- Memory problems
- Health problems
- Loss of independence
- Reduced income
- Depression
- Loss of peers/ social withdrawal

- TBI Disability Based
- Mobility problems
- Functional loss
- Memory and cognitive problems
- Sensory impairments
- Health problems
- Loss of independence
- Reduced income
- Depression
- Loss of peers/ social withdrawal

### TBI: A young person's injury grows into a lifetime of disability

- Over 5 million Americans living with disability related to TBI
- 1,200,000 Americans and 590,000 Canadians injured each year (all levels of severity)
- 84% have co-occurring disabilities
- Lifespan of a person with TBI injured before age 30 is 78.6 years (NIH, 2000)
- Effects of the injury on "neuronal reserve" accelerates aging (Ruff, 1997)



### TBI and Age: Review of the Literature

- Cognitive Decline
  (Himanen, 2006; Klein, 1996)
- Poorer FunctionalOutcomes (Testa, 2005)
- Delayed post-surgical complications (Howard, 1989)
- Deficits more pronounced (Goldstein & Levin, 2001)

- Arthritis and sleep problems (Colantoni, 2004)
- Increased seizures, chronic pain and medication use (ACRM, 2001)
- Persistent affective and behavioral symptoms (Cattelani, 1998; Colantonio, 2004; Hibard, 1998; Hoofien, 2001; Thomsen, 1984)

#### Age at Injury and Outcome

- Direct correlation between age and outcome with higher rates of severe disability, PVS and death for >55
- Severe disability, PVS and death rates for the age 15-24 cohort were 50% of the rate for >55
- 34% of the age15-24 cohort experienced moderate to severe disability at the 6 month interval
- Sources: Hukkelhoven, C. et al, J. of Neurosurgery 99:666-673, 2003



#### Age and Recovery Issues

- Adult brain has a decreasing ability to repair itself as it ages because of a decreasing # of neurons
- Greater likelihood of repeated insults to the brain based on age
- 40-50% increase in the odds of a poor outcome for every 10 years of age
- Source: Hukkelhoven, C. et al, J. of Neurosurgery 99:666-673, 2003



### The high costs of a lifetime of disability

- Highest rate among 15-19 year old Males: 550/100,000 vs 115/100,000
- Increased survivability for younger individuals
- Lifetime costs projected \$4.5 to 5 million (Livneh and Antonak, 1997) and \$8 to 17 million (Bilmes,L,2007)



#### Costs of Care Increases With Age

- TBI costs associated with acute care increased at twice the rate for general medical care (Kreutzer, 2001)
- Increased motor disability associated with total charges (Vangel, 2005)
- Coping and adaptive strategies learned in rehabilitation fail as individuals become middle aged and senior citizens for mild to moderate injuries (Klein, 1996)







- 3 Years Post Injury:
- 50% of admissions for orthopedic and reconstructive surgery
- 15% for seizures
- Psychiatric hospitalizations doubled in years 1-2, leveling off in year 3
- Cifu, 1999

- 5 Years Post Injury:
- Orthopedic and reconstructive surgery admissions declined
- Incidence rate for seizures and psychiatric admissions increased
- Marwitz, 2001

### Long term healthcare resource utilization

- Severity of injury, physical/cognitive and psychosocial disability all predict service utilization
- Individuals 6-48 months post injury used services related to restoration of function
- Individuals 72- 204 months post injury used services in response to life changes such as loss of relationship or caregiver
- Hodgkinson, 2000

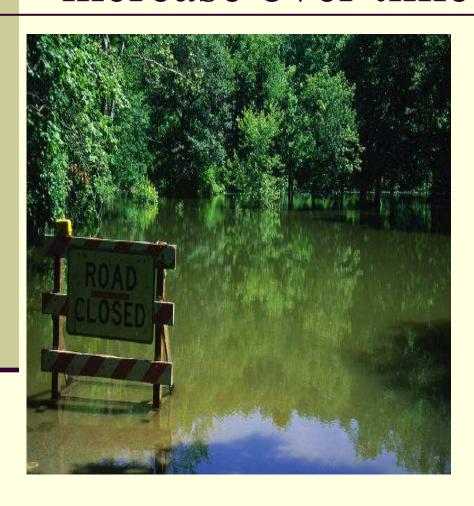


### Life Focus Changes and Shifts due to Disability

- Altered social role and function in school and work
- Independence outside of the family
- Changing social roles in and outside of the family
- Shift to dependent role
- Reduced access to social network
- Social Exclusion
- Source: NRIO Outcome Study 1997-2006



### What are the barriers which increase over time?



- Functional capacities diminish
- Emergence of additional medical problems
- Changes in social role and relationships
- Loss of life activity focus
- Higher rates of psychological problems (depression, addiction, suicide)
- Housing and community access problems
- Social network and support failure
- Aging and caregiver issues
- Source: NRIO Outcome Study 1997-2006

### Brain Injury: Not a Single Disability

- Severity related factors
- Increased survivability with greater functional deficits
- Increased comorbidity
- Mental health and substance abuse problems
- Social network deterioration
- Caregiver stress
- Mobility and access issues
- Reduced income, disability related poverty



# Brain Injury Disability and Health Disparities

- Economic and social status affect health status
- Poor health practices due to cognitive problems
- Limited resources/insurance for healthcare
- Reduced health literacy
- Increased rates of: obesity; hypertension; depression; diabetes
- Increased stress
- Sources: Williams, David, 2006; Willis, Diane, 2002



### Disability and Future Healthcare Needs

- Increased vulnerability to specific diseases cause premature entry into "frail elderly" group
- Decreased access to health maintenance and wellness programs
- Early onset of chronic health problems associated with disability
- Likelihood of experiencing new health conditions related to functional loss
- Likelihood of experiencing longer and more complicated treatment for health problems
- Greater needs for DME, poorer adjustment to assistive devices
- Source: DeJong, 1997



#### Concept of "Frail Elderly"

- At 80, the average person has three disabling conditions
- A person with brain injury has disabling conditions which occurred prior to age 80 which may worsen in old age
- Caregivers experience aging issues affecting their ability to provide assistance
- The ability to access to care diminishes



#### What about "Caregivers"?

- Age/gender of caregivers
- Health problems of caregivers
- Physical capacity of caregivers
- Financial Issues
- Limited resources
- Source: Rosalynn Carter Foundation, National Quality Care Coalition Report, University of Florida, 2006



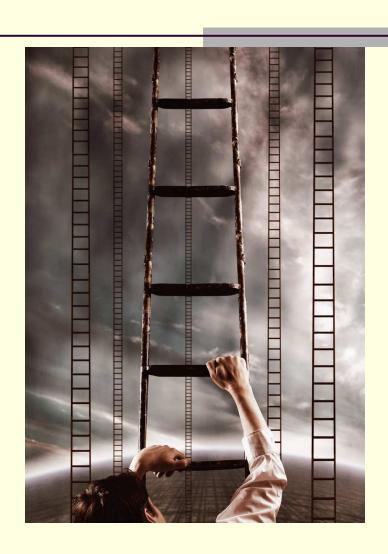
# Consequences of Long Term Disability

- Disability and/or death of a caregiver
- Consideration of placement outside of the home/ loss of housing choice
- Economic losses/ Disability Related Poverty
- Being physically dependent on others for care



#### Care needs and social isolation

- Study involved 454
   Canadians, average 13
   years post TBI
- 66% required ADL assistance
- 75% not working
- 90% dissatisfied with social interaction
- 47% not talking with others by telephone
- 27% never socialize at home
- 20% never visit others
- Source: Dawson and Chipman, 1995



#### **Priority Issues of Family Members**



- Functional physical limitations
- Chronic medical care needs
- Reliance upon others for basic care
- Transportation
- Depression
- Cognitive (memory) problems
- Behavior and Anger Management problems
- Source: NRIO Outcome Study, 1993-2005

#### Caregiver Perception of Problems Associated with long term outcomes



- Decreased activity outside of the home, isolation
- Need for emergency hospitalization due to medical and psychiatric events
- High physical dependence, altered functions within family
- Accelerated aging
- Age issues of caregivers, "burnout"
- Source: NRI Outcome Study 1993-2006, NRIO Outcome Study 1993-2006

### Impact of Brain Injury on caregivers

- 18% of care recipients are 45-65
- 75% of the caregivers are female, older than the population at large; 80% not employed outside of the home
- Higher incidence of healthcare problems for caregivers
- Household incomes below the national average
- Source: Decima, 2002



# Psychological Issues Faced by Caregivers

- Behavioral, social, cognitive and emotional changes have a greater effect on caregivers than physical needs
- Personality disorders affect caregivers' mental and physical health (Andrews, 2002; Hooker, 2000)
- Wives of men with TBI experience greater distress and emotional and physical adjustment than wives of men with SCI (Levor and Jansen, 2000)
- Duration of disease/disability is a strong predictor of mental health problems in caregivers (Thommassen, 2002; Carter, 1998)



# Caregiver and Individuals: Shared Issues and an Ambiguous Loss

- Extended period of grievance (Mobile Mourning, Haffey and Muir, 1984) and response to lifestyle and functional changes (Partial Death Syndrome, Cree, 2003; Duff, 2002; Antonak, 1983)
- Increased risk of violence as victim or perpetrator
- Increased rate of rehospitalization for psychiatric problems and seizures (Cifu, 1999)
- Social isolation and exclusion affecting both the individual and caregivers



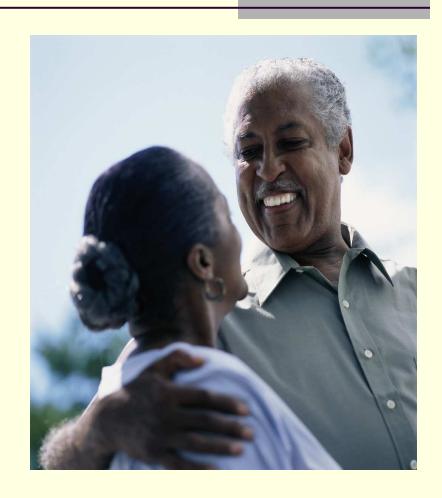
### Long term Caregiver and Family Issues

- Caregivers as "hidden victims" reporting "mental distress and poor health" 46% more than noncaregivers
- 61% of caregivers are women, managing competing family responsibilities
- Care requiring >23 hours/week
- Responsibilities include: case management; transportation; housing; personal care; activities; financial management; medication administration
- Source: Rosalynn Carter Institute, National Quality Care Coalition, University of Florida, 2006



#### Family Response to Disability

- Finding time for themselves 35%
- Managing challenging behavior 31%
- Needing information/access to financial help 36%
- Needing information on activities to do 27%
- Source: Rosalyn Carter Institute, National Quality Care Coalition, University of Florida, 2006



# Post Rehabilitation Chronic Medical Problems Experienced by Individuals



- Seizure disorders
- Respiratory problems
- Late onset of swallowing problems
- Skin integrity
- Diabetes
- Circulatory problems
- Contractures and orthopedic problems
- Stoma care and GI complications
- Pain management and headaches
- Fatigue
- Source: NRI Outcome Study, 1993-2006; NRIO Outcome Study, 1993-2006

### 10 Year Perspective: Emergence of Psychiatric and Substance Abuse Problems

- Psychiatric and Substance abuse problems which predated injury remained as interfering problems at the 1, 2 and 3 year intervals for individuals with moderate to moderate/severe injuries and resulting disabilities
- Psychiatric and substance abuse problems had a lower occurrence rate pre injury for the individuals with severe injuries, but remained as an interfering problem post discharge for individuals who initiated substance use post-injury
- Emergency psychiatric hospitalization was found to occur as a result of: seizures, relationship problems, medication noncompliance and substance abuse
- Psychiatric and substance problems were associated with social network, community living and life activity problems
- Source: NRIO Outcome Validation Study, 1993-2006

# Family Response to TBI Disability: What Works!

- Coping style and satisfaction with social support network were more significant factors than injury severity in assessing a positive family response
- A low number of "unmet needs" and a low number of escape/avoidance strategies were predictors of a positive family response
- Family functioning in the years post injury were an indicator of adjustment to disability for both the individual and their family
- Source: Sanders, 2003, Baylor College of Medicine, Institute for Rehabilitation and Research



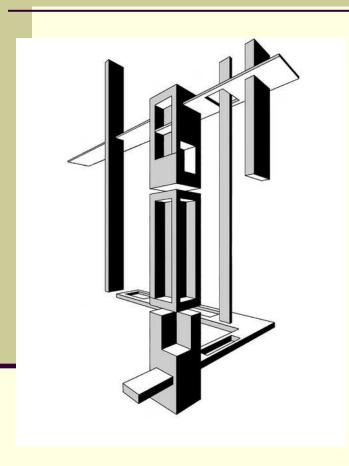
#### 10 Year Perspective: Social Role Return

- Over the 10+ year span of the study, an average of 37.3% report returning to and maintaining their primary social role without modification
- 43.1% report experiencing a change in social role status requiring support from family members
- Follow-up study observed "no regression" in social role return and noted that individuals were reassuming greater aspects of their pre injury social roles as time progressed
- Source: NRIO Outcome Validation Study, 1993-2006

### 10 Year Perspective: Independence in the Community

- In the 10 year period, average of 42.2% receive "no to minimal" paid support at the time of program discharge
- Severity factors at discharge influence support needs
- As level of independence increased over time, hours of paid support decreased and was maintained
- Individuals with greater physical disabilities report increased hours of unpaid (family) support which also decreased over time
- Independence level was maintained over time
- Source: NRIO Outcome Validation Study, 1993-2005

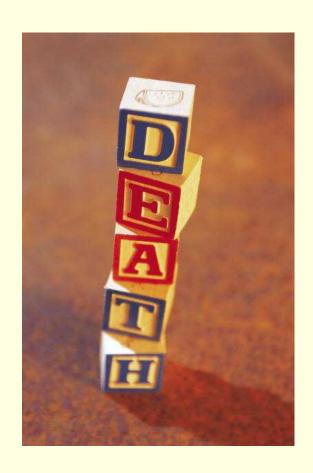
### Maintaining Independence: Clients' Perspective at the Ten Year Point



- Housing Choice
- Returning to live with parents or family in a dependent status
- Difficulty in accessing services outside of the home
- Difficulty in obtaining TBI support services
- Finding resources with brain injury expertise
- Economic changes
- Source: NRIO Outcome Study, 1993-2005

## Disability and Death of a Caregiver

- Abrupt transition in relationship, personal care, housing and healthcare routines
- Problems associated with the loss of a loved one
- Finding other family members or paid caregivers to assume care responsibilities
- Economic upheaval



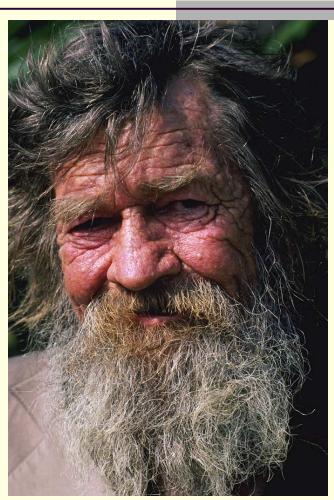
#### Caregivers: A Fragile Support System for the Future



- The aging of the population living with a brain injury- 18% of care recipients are 45-65
- Increased survivability and increased disability
- Relationship of comorbid conditions to primary disability
- 75% of caregivers are female, older than the population at large, 80% not employed outside of the home
- Caregivers themselves face the problem of aging
- Household incomes below the national average (Decima, 2002)

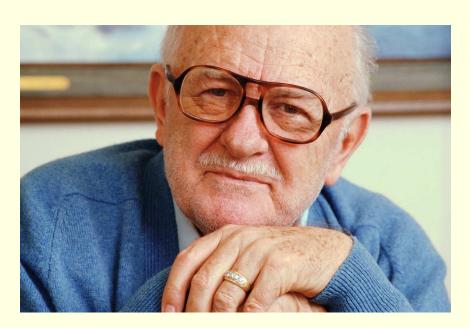
# Diminished functions and the aging process

- Physical
- Cognitive
- Behavioral
- Changes and further loss of abilities moves the aging process ahead



#### Increased likelihood for Dementia

- Link to Alzheimer's and other Dementias (Salib and Hillier, 1997)
- Pre-existing cognitive impairments linked to Vascular Dementia (De Deyn, 1999)
- Performance of middle aged individuals with TBI mirrors senior citizens without TBI (Klein, 1996)
- Increased risk for brain atrophy (Filipovic and Teofilovski-Parapid, 1998)



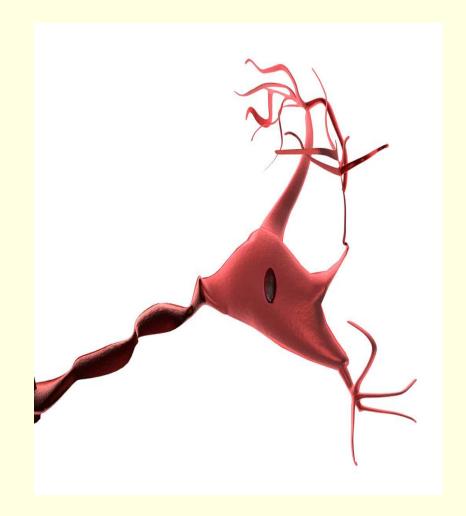
# Mental Health Issues and Aging with a Brain Injury

- What happens to the individual with psychiatric issues as they age?
- Greater likelihood of crisis
- Reduced ability to self manage symptoms and required medication
- Greater interference of symptoms with functional abilities



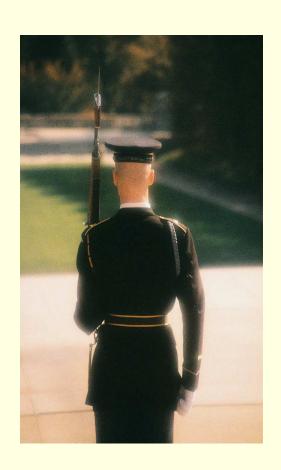
## Neuropsychiatric Features of Brain Injury

- Psychosis
- Depression
- Anxiety Disorders
- Mania/ Affective Disorders
- Post Traumatic StressDisorder
- Aggression/Irritability



### Living with "Emotional Shrapnel": Injuries beyond the physical realm

- Psychological effects of the injury on self image and social role functioning
- Onset of social withdrawal
- High incidence of depression
- Substance Abuse as selfmedication
- Core psychological issues never addressed
- Emergence of psychiatric symptoms and risks such as suicide



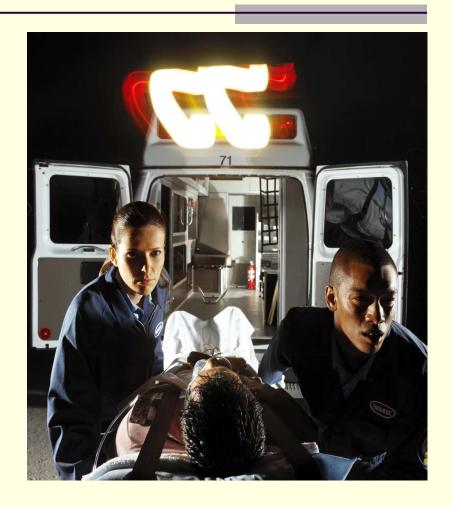
### PTSD: Mental health problem or a permanent change in brain function?



- Rates of generalized anxiety, major depression and PTSD were 17% after tour of duty for Iraq veterans and 11.2% for Afghanistan veterans (Hoge, New England J. of Medicine 2005)
- Intensity of exposure to combat/firefights, IED's, handling the dead/injured and frequency of injury increased risk for PTSD (Hoge, 2005)
- Increased activity in amygdala and reduced activation of the anterior cingulate gyrus and medial prefrontal gyrus seen in individual with PTSD (Friedman, M., Neuropsychiatry Review Jan. 2006)
- Resilience seen in individuals capable of mobilizing neuropeptide-Y (NPY) (Friedman, M., 2006)
- Changes to the function of the brain occur with PTSD
- Why are some people more resilient than others?
- What happens to the soldier with a brain injury and PTSD?

### Compassion Fatigue and PTSD: The same disease process affects the person and their caregivers

- First responders and crisis workers absorb the same traumatic stress as those they help (Beaton and Murphy, 1995)
- The concept of "contagion": spread PTSD symptoms between people (Figley, 1997)
- Family members become traumatized caring for their injured loved one (Barnes, 1997)
- Emergency medical personnel experience PTSD symptoms in response to catastrophic injuries (Figley, 1982)
- Secondary Vicitimization (Figley, 1997)



#### Increased Risk for Suicide



- Response to depression
- Social isolation and exclusion
- Diminished impulse control/ self regulation
- Reduced problem solving ability
- Highest rates among males 15-24 and 65+

### Increased Risk for Substance Abuse

- Pre injury factors involving substance use/abuse
- Exacerbated or emerging use post injury
- Self-medication, response to depression, mood state changes
- Boredom, loss of life focus, withdrawal and exclusion
- Family difficulties
- Loss of peer group and social network
- Source: NRIO Outcome Validation Study, 1993-2006



#### Long term survivor studies



- WWII Study followed 1776 battle casualties injured between 1944-1945 in U.S. Navy Hospitals
- 548 identified as TBI vs.1228 without TBI
- Risk of Alzheimer's Disease increased with severity (.75 Mild to 4.5 Severe)
- Earlier onset of dementia for TBI group

- Life prevalence rate of depression was 18.5% for TBI vs. 13.4% non-TBI. Risk increased with age and injury severity
- PTSD was seen in 77% of the TBI group vs. 59% without TBI
- Source: Plassman, BL et all, Neurology, 2000
- Plassman and Evans, 2<sup>nd</sup> Federal Traumatic Brain Injury Conference, 2006

### A view over three wars: surviving with multiple disabilities

- Iraq/Afghanistan 1KIA 16 wounded, 5-8 disabling conditions involving 50,000+ individuals
- Vietnam 1KIA 2.6 wounded,3 disabling conditions
- Korea 1 KIA 2.8wounded
- Increase in survivorship creates more individuals living with multiple disabilities
- Source: Bilmes, Kennedy School of Government Study, 2007



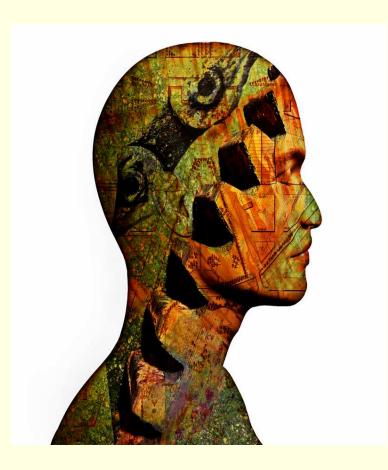
## Veterans: An enhanced risk for disease processes

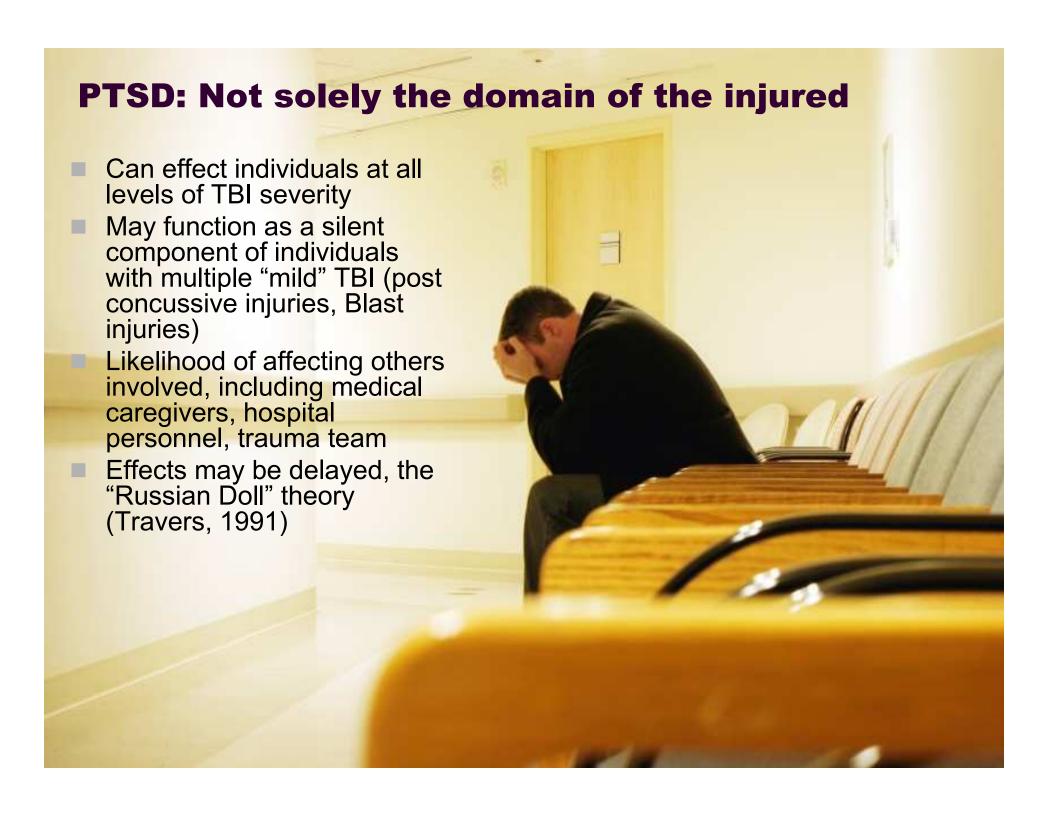
- Dementia
- Depression
- Stroke
- PTSD
- In Iraq/Afghanistan, Blast Injuries associated with polytrauma: 40% had TBI and 50% of the TBI cases had moderate to severe injuries/disabilities
- Multiple blast injuries are being identified as consistent with profile of multiple mild TBI's (Collins, Treatment of the Combat Injured, 2006)



### The genesis of PTSD

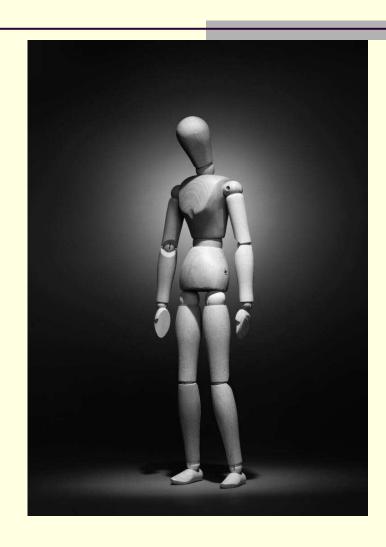
- Exposure to (abusive) violence
- Exposure to deprivation
- Loss of meaning
- Loss of control
- Source: Shay, Achilles in Vietnam, 1995





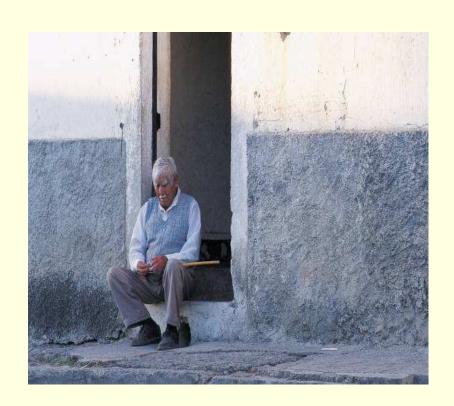
#### Cycle of Trauma

- Terror event leading to hyperarousal
- Disconnection/withdrawal from psychological, physical and social issues
- Responding to "the unspeakable" (the trauma event)
- Re-experiencing the event, over time with enhanced feeling states
- Experiencing psychological "numbing" to avoid feelings/thoughts
- Further withdrawal
- Loss of self worth
- Source: Herman, J., Trauma and Recovery, 1997

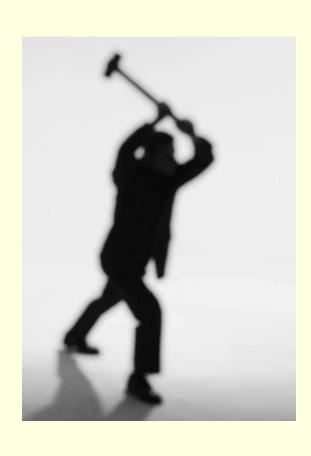


### PTSD: The feeling state experience

- Feeling "dead already", experiencing loss as total
- Feeling "guilty for surviving"
- Thinking about suicide
- Source: Shay, 1995

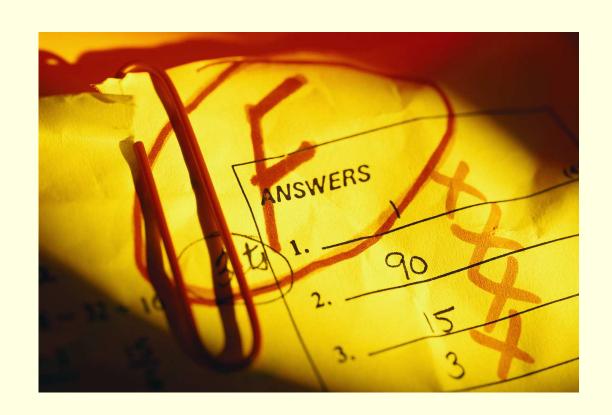


#### Anger formation and PTSD



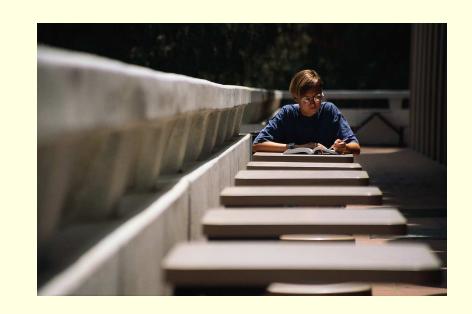
- The concept of "berserk rage", out of control state in response to trauma event
- Feeling alone with wounds, both psychic and physical
- Indignant/angry that others won't/don't understand pain and loss
- Source: Shay, 1995

### Brain Injury in Childhood: A prelude to future disability?



### Long Term Implications for Children with TBI

- High survival rate from moderate to severe injuries
- Likelihood of future psychiatric disorders, learning problems and psychosocial adjustment problems
- Early age at injury related to problems surfacing 5-8 years post injury
- Social isolation from peers caused by functional and behavioral issues
- Need for extended family supports



### What happens to individuals injured as children?

- Interaction between brain injury and developmental processes
- Psychosocial adjustment problems, onset of psychiatric disorders
- Family system/caregiver stress
- Lifetime consumers of specialized services
- Lifetime of disability



### Today's Child with TBI is Tomorrow's Elderly

- Effects on maturational processes, long term issues associated with "Cognitive Stalling" (Campbell, 2007)
- Continued learning and cognitive problems
- Self-image and evolution of person
- Limited access to social network
- Caregiver and support issues



### Long Term Outcome Issues for Children

- Development, academic and social problems
- Psychiatric, psychological and behavioral problems emerge (Max, 2004)
- Alienation from peer network
- Social adjustment problems
- Transition from family does not occur
- Isolation within family



#### Pediatric Characteristics: NRIO Study

- Average Age at Injury 10.7
- Average age at discharge 13.4
- Average GCS 6.8, range 3-15
- Average period post TBI was 8.5 months
- 100% MVA with 60% as Pedestrian
- 100% presented with academic and cognitive problems
- 80% with behavioral problems
- 60% with psychological/adjustment to disability problems
- Source: NRIO Outcome Validation Study, 1997-2006

#### **Pediatric Outcomes: NRIO Study**

- 80% participating in modified academics or vocational training with moderate (2-4 hours/day) to no to minimal supports (0-2 hours/day)
- 20% participating at pre-injury level with peer classmates
- Reduction in required supervision from family members
- Increased participation in community/school independence with moderate to minimal support levels
- 40% requiring ongoing psychological or behavioral support
- Multi year durability data indicates need for ongoing support services to maintain positive family, school, social and psychological adjustment
- Source: NRIO Outcome Validation Study, 2005

#### Children with TBI: Two Years Later

- 40% of the participating children required modified school programs, 20% returned to grade level participation
- 60% of the participating children re-entered school with a modified social role
- 40% of the families performed attendant care functions at the two year point
- 40% of the participating children required psychological and/or behavioral support
- Source: NRIO Outcome Study 1993-2006

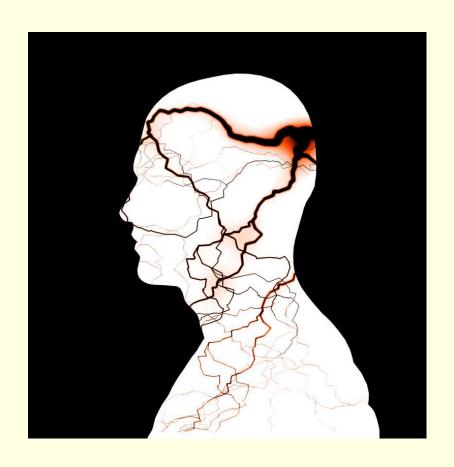


### The Long Term Perspective



### Clinical Profiles: The Years Post Injury

- Status of individuals who are 10-25 years post-injury
- Loss of specific gains made in initial rehabilitation
- Onset of specific medical problems
- Increase in care needs



# An accelerated decline caused by injury severity

- Health issues related to long term injury effects and healthcare access
- Early onset of physical and cognitive decline
- Psychological response to a long term disability
- Social exclusion and social withdrawal reduces access to care opportunities
- Potential for reduced health literacy due to cognitive deficits



### The process of aging with a TBI

An accelerated aging process reduces the level of independence attained by the individual



#### Diminished physical functions

The reliance upon others to provide care increases over time, further reducing independence and affecting the person's ability to participate at home and in the community



#### Diminished cognitive abilities

 Functions such as memory, decision making and problem solving may decline as the person ages and the gains made in rehabilitation will erode



### Social Role Changes

Social role return is a significant aspect of long term outcome which can change as the person ages and requires more assistance, care and support from others



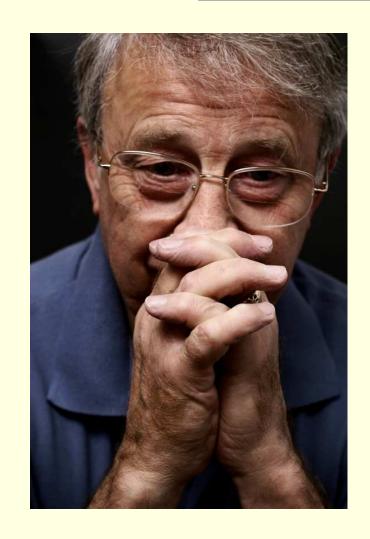
#### Support and care needs increase

As functional abilities decrease over the course of a person's life they will require more support from family and paid caregivers.



## Economic factors associated with aging

Living with a disability requires financial resources. The process of aging may place additional demands on the already limited financial resources and exert pressure on the individual and their family effecting all aspects of life.



### Shane, Age 50, Injured at 28

- Aspiration pneumonia at age 48
- Severe swallowing problems required extensive therapy to return to oral feeding at age 44
- Extensive debilitation and fatigue problems following pneumonia
- Now requiring total physical assistance
- Death of mother in 2006, increased medical problems for father, aged 86
- Care needs increasing since age 44
- Further cognitive deterioration

### Joyce, Age 60, Injured at age 43

- Aspiration pneumonia at age 56
- Swallowing problems requiring monitored eating
- Temperature control problems related to the onset of medical crises
- Severe gait and balance problems, unsafe ambulator
- Total physical assistance
- Limited family involvement



### James, Age 62, Injured at 45

- Increased memory problems and confusion
- History of post-TBI anger and violence towards spouse
- Requires cues and reminders for living skills
- Poorly controlled diabetes, cannot self-test or administer insulin
- Diagnosed with sleep apnea at 60
- Limited contact with wife

### Richard, Age 60, Injured at 41

- Power wheelchair user due to neuromotor and orthopedic problems
- Severe Circulatory problems involving lower extremities
- Skin breakdown due to incontinence
- Poorly controlled diabetes, non compliance with diet
  - and medications
- Increased confabulation
- No family contact

### Tim, Age 47, injured at 37

- Increasing problems with diabetes management, increase in insulin requirements
- More frequent periods of agitation and violence
- Experienced negative effects of psychiatric drugs used to manage his behavior, medications withdrawn
- Family questions their ability to care for him at home

### Miriam, Age 66, injured at 47

- Increased balance and gait problems, unsafe independent walker
- Experienced falls resulting in fractures
- Increased judgment problems, especially as related to physical safety/capacities
- Limited endurance, wheelchair user outside of the home
- Sister and mother are unable to care for her at home due to their ages and situations

### Early onset of problems associated with aging

Increased need for healthcare services

Increased needs for living supports and attendant care

Greater mobility and access problems
Aging family caregivers
Decreased level of participation



### More People Survive, Less Resources to Share

- "Sicker and Quicker" reduced stays in acute medical care
- More survivors with greater disability levels and comorbidities
- Increased lifetime costs associated with severity and longevity
- Source: NRIO OutcomeStudy 1997-2006; NRIOutcome Study 1993-2006



### Today's Injuries/ Tomorrow's Disabilities

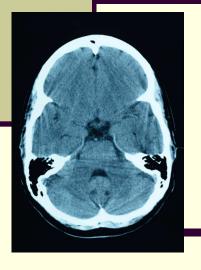
- Increase in medical technology preserves life for individuals with severe injuries
- Increase in survivorship increases the extent and level of disabilities experienced by people
- Improvements in healthcare extends the lifespan of people living with disability



### Aging and Brain Injury: How can we address the long term needs of people living with TBI

- Increase availability of accessible housing, transportation and community supports
- Eliminate healthcare disparities
- Provide economic supports and income supplements to avoid disability based poverty
- Provide lifetime supports for caregivers and family members
- Address critical transition events which trigger crises and problems
- Make available professional healthcare resources who can address the issues of aging with a brain injury

# The Graying of Brain Injury: Aging and Lifespan Issues



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nrio.com traumaticbraininjury.net