

Maintaining Intimacy After Traumatic Brain Injury:

Identifying Solutions to Difficulties in Intimacy

Rolf B. Gainer Ph.D.

Diplomate, ABDA

**Neurologic Rehabilitation Institute
at Brookhaven Hospital**

Neurologic Rehabilitation Institute of Ontario

How can we develop a better understanding of the problems and potential solutions related to sexuality and intimacy following traumatic brain injury?

- # What issues affect the individual?
- # What issues affect the significant other?
- # What happens in relationships and families?
- # What are the rehabilitation implications?

Limited exposure of the problem

- # Frank discussion of sexual problems following TBI is often limited
- # The focus on physical recovery overshadows return of the intimate aspects of living and relating
- # Increased dependency forestalls addressing issues in rehabilitation and social role return phases
- # Societal view that sexuality is rarely associated with disability
- # Discomfort of others, including professionals, in discussing the problem

Misperceptions Regarding Sexuality and Brain Injury

- # The person has returned to a childlike state
- # It's our job to take care of them
- # Brain injury effects do not occur "below the belt"
- # Sex will/could cause problems
- # It's not the same person I married/
no longer the same
- # I feel like I'm cheating
- # Will they know what to do?



"OK, maybe a little hanky, but no panky!"

Research in Brain Injury and Sexuality

- # Arrested sexual self concept due to age at injury. *Blackerby, 1987*
- # Effect on motivation and initiation of frontal lobe injuries. *Blackerby, 1987*
- # Lessened sexual arousal due to sensorium loss. *Hayden and Hart, 1986*
- # Spousal frustration secondary to reduced interpersonal sensitivity. *Lezak, 1978*
- # Sexual dysfunction more common in intellectually impaired group. *Kosteljanetz, 1981*

Changes in Sexual Behavior Associated with TBI

Source: J. Ponsford, 2003

# Tiredness and fatigue	47%
# Decreased mobility	31%
# Low confidence	31%
# Feeling unattractive	23%
# Pain	22%
# Difficulties in Communicating	21%
# Loss/decrease of sensitivity	19%
# Other reported problems: decline in relationships; limited access; arousal/sex drive; behavior	

N=208 (69% Male)

Divorce and Brain Injury

- # 50% of marriages and primary relationships fail within 24 months post-injury (*Burke and Weslowski, 1989*)
- # Brain injury produces stressors within the social network that produce failure in relationships with family, friends and loved ones
- # Problems involving social behaviors, including intimacy, sexuality and self-regulation create significant stressors in relationships
- # Cognitive and emotional changes in the person effect the relationship
- # Increased dependency needs and social role changes cause deterioration in primary relationship

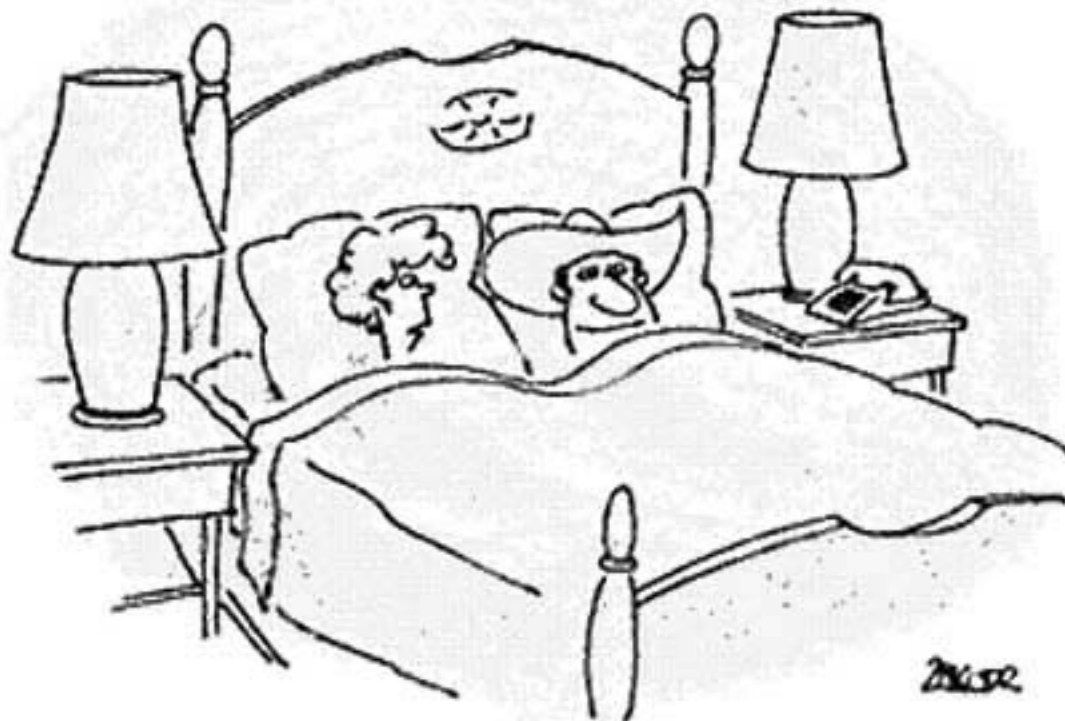
Psychological Issues Related to Intimacy Problems

- # Depression/ sadness/ grief
- # Amotivation/ loss of libido/hyposexuality
- # Abulia/ apathy/loss of pleasure in living
- # Manic states including hypersexual behavior
- # Hypersexuality related to specific lesion sites or interictal periods

Couples Issues

Frequently reported issues include:

- # Loss of interest
- # Decrease in coital frequency
- # Reduced expression of affection
- # Perception of “sex appeal”
- # Worsened communication between partners
- # Sexual avoidance
- # Sexual dysfunction, either party



"Yippie-ti-yo-ki-yay? Is that all you ever have to say?"

Intimacy Problems Increase After Brain Injury

- # Wives of brain injured partners report “men are more self-oriented and exhibiting more childlike dependency (after the injury).”
Rosenbaum and Najenson, 1976
- # Inflexibility (20%), inappropriate public behavior (40%), self-centeredness (43%) and decreased self control (47%) mitigated against sexual readjustment. *Oddy and Humphrey, 1980*
- # Wives report that they receive less expression of affection after injury. *Peters, 1990*

Changes in sexual functioning after injury

- # Sexual arousal and orgasmic difficulties seen in 57% of individuals.
Kreutzer and Zasler, 1989
- # Spousal anorgasmia increased from 27% to 64% after the injury. *Garden, 1990*
- # 67% of the TBI group report decreased self- confidence and sex appeal.
Kreutzer and Zasler, 1989

Physical Issues Related to Sexual Dysfunctioning Following TBI

- # Hypogonadism effect seen in 24% of severe TBI cases (coma more than 24 hours).
Clark, 1988
- # Inappropriate sexual behavior seen in 38% of individuals with frontal lobe injury.
Sabhesan and Natarajan, 1989
- # Temporal lobe injuries mediate sexual preference. *Lilly, 1983*

Sexuality and Brain Injury

What are the changes which affect sexuality?

- # Physical
- # Cognitive
- # Behavioral
- # Psychological
- # Social Role

Cognitive Aspects of Sexuality

Sexuality is a complex function

- # Problem solving
- # Memory
- # Sequencing
- # Maintaining attention
- # Shifting sets
- # Denial

Physical Changes Following Brain Injury

- # Lost/diminished functions and capacities
- # Pain
- # Fatigue
- # Motor control
- # Sensation/perception
- # Strength/endurance
- # Performance

Behavioral Changes Affecting Sexuality

- # Impulse Control/reduced capacity to self-regulate
- # Anger
- # Withdrawal, alienation from others
- # Denial
- # Emergence of psychiatric and substance abuse problems

Social Role Return

- # Increased dependence on others
- # Different social/relationship role
- # View of self with partner
- # Partner's response and view of partner's response
- # Adult individual living in parental home post-TBI
- # Diminished social network

Psychological Issues

- # Depression
- # Unresolved grief and loss
- # Impulse control problems
- # Perception of diminished self-worth
- # Perception of unattractiveness

Partnering Issues

- # Individual requires a high level of care from partner
- # Role changes: independent to dependent
- # Caregiver stressors
- # Time
- # Not knowing what would happen/fear
- # Negative feelings/thoughts
- # Psychological reaction of partner to TBI of loved one
- # Withdrawal from relationship
- # Response to physical, cognitive, behavioral and psychological changes

Stress and Relationships

Is this the same person?

- # Understanding the effects of the person's injury and relationship to intimacy
- # Developing an effective and caring relationship
- # Addressing old, maladaptive patterns
- # Role of children and others
- # Creating realistic expectations

Maintaining Former Relationships

Coping with the changes

- # What's old?
- # What's new?
- # Responding to problems
- # Preventing the loss of the emotional bond
- # Achieving a loving relationship

Initiating New Relationships

Starting Over Issues

- # Self-image/self-worth
- # Learning to date
- # Explaining the disability issues
- # Maintaining realistic expectations for both parties

Using Interactional “Scripts”

Creating a method for initiating and maintaining a relationship

- # Conversation
- # Negotiating time and activities
- # Understanding boundaries
- # The “yes” and “no” words
- # Attention to cues

Addressing Self-Regulation

- # Controlling impulsive behaviors
- # Relearning intimacy related behaviors
- # Relearning non-sexual demonstrations of affection

Treatment and Rehabilitation Implications

- # 94% of staff in a rehab setting anticipated sexual adjustment problems if sexuality was not included in rehab. *Hough, 1989*
- # Early incorporation of self-stimulation in the normal adaptive awakening process. *Blackerby, 1987*
- # Education and counseling in the middle stage of recovery. *Butler and Satz, 1988*
- # Addressing pre-morbid factors through social skills training. *Blackerby, 1987*
- # Use of behavioral treatment to address hypersexual conduct. *Zencius, 1990*

Self-Image Issues Affecting Intimacy

- # View of self as “different” or “damaged”
- # Not feeling desirable or attractive
- # Focused on physical deficit(s) as barrier
- # Treatment needs to address self-concept issues

Creating and Maintaining a Sexual Relationship

- # Intimacy as a mutually shared relationship
- # Negotiating time, place and space
- # Developing reciprocity
- # Recognizing mutual wants and needs
- # Picking a pace for intimacy
- # Feeling respected, wanted and loved

Treatment for Behavioral Problems Affecting Intimacy and Sexuality

- # Use of behavior learning strategies to address hypersexual behaviors
- # Education and counseling for individual, couple and family regarding aspects of social role return
- # Use of cognitive restructuring, alternative strategies, sexual aids and traditional behaviorally-based sex therapy techniques
- # Addressing time and replace issues for uninhibited sexual expression rather than suppressing the behavior

Staff Training is Vital to Sensitizing Staff to Intimacy Issues

Training curriculum should include:

- # Sexual dysfunctions
- # Approaches to spousal education
- # Establishing realistic expectations for sexual adjustment
- # Effect of cognitive deficits
- # Client perception of sexuality issues
- # Dating resources
- # Gay and lesbian issues

*Presented as a learning activity for rehabilitation professionals
by the Neurologic Rehabilitation Institute at Brookhaven Hospital*

- # Neurobehavioral rehabilitation
- # Complex care
- # Dual Diagnosis
- # Hospital and community-based programs
- # Supported Living Programs
- # Accredited by JCAHO
- # 888-298-HOPE or www.traumaticbraininjury.net