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. *Kostelijanetz, 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)
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/hypossexuality
- 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
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