# SEX
## AND THE
# Single Synapse:

Maintaining Intimacy Following a Traumatic Brain Injury

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## 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?

# How do sexuality and intimacy relate to a satisfactory return to independence?

- 20% of the participants with TBI report “Satisfied with Life” at the 1, 5 and 10 year post injury points

*Source: Traumatic Brain Injury National Data Center, Traumatic Brain Injury Model Systems Database Update, Millis, 2004*

# 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?"

# Unique Reactions of Wives of Men with Brain Injuries

- No sexual outlet:  42%
- I'm married, but I don't have a husband: 42%
- I'm married to a stranger:  32%

*Maus-Claim and Ryan, 1981*

# Limited exposure of the problem in rehabilitation settings

- 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

"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)*
- Adaptation and Accommodation are neglected following TBI, (Trudel, 2006)

# 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%

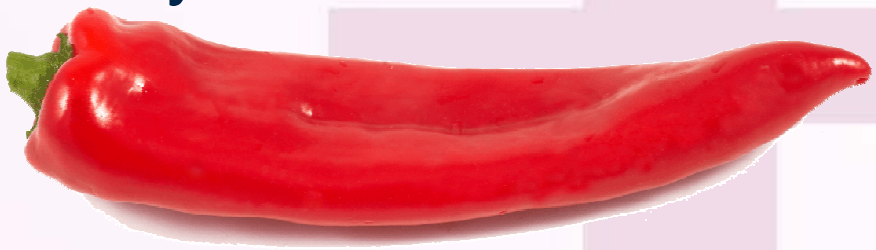
*Other reported problems:*
*decline in relationships; limited access; arousal/sex drive; behavior N=208 (69% Male)*

# Sexual Behavior Post TBI

- Role of depression, anxiety, cognitive impairments, amotivational states and behavioral dyscontrol impact sexual functioning
- Location of lesion site associated with satisfaction/dissatisfaction with sex life (frontal vs. nonfrontal) (Sandel, 1996)

# Difficulties Associated with Sexual Behavior Post TBI

- Sexual energy, desire and drive
- Reduction in sensation and orgasm
- Problems with positioning, movement and pain
- Changed body image, reduced self-confidence and mood state problems
- Decreased ability to sexually satisfy partner
- Sexual disinhibition
- Hypo and Hypersexuality



# Gender Specific Differences

- Perceived desexualization of women with disabilities
- Problems with arousal, vaginal lubrication, pain
- Endocrine disorders and depression were predictors of sexual difficulties (Truesdel, 2005)
- Lower marriage rates for women with disabilities than men with disabilities
- Disabled women were as sexually involved as their non-disabled peers, but were experiencing disorders of sexual function at a higher rate. (Hibbard, 2000)

# Age and Social Factors Associated with Sexuality and TBI

- Delayed entry into dating for individuals injured in childhood
- Social pressures against dating a disabled person
- Effect of low self esteem and self defeating behavior
- Limited mobility and community access

# Medications and Sexual Behavior

| | | | |
|---|---|---|---|
| Antidepressant | Prozac, Elavil, Norpramin | Control/improve mood | Delay orgasm |
| Antispasmodic | Baclofen, Probanthine | Reduce/control spasms | None |
| Antihypertensives | Inderal, Beta Blockers | Control blood pressure | Decrease sexual drive |
| Antiseizure | Dilantin, Tegretol, Depakote | Reduce/control seizures | Decrease sexual drive, increase fatigue |
| Antihistamine | Actifed, Claritin, Atarax | Control allergy symptoms | Older meds decrease sexual drive |
| Anti-inflamatory | Advil, Naprosyn | Control inflamation, reduce pain | Increase sexual drive and response |
| Antibiotics | Cipro, Penicillin | Control infection | Increase potential for yeast infections |
| Antiemetics | Reglan, Compazine | Control nausea | Decrease sexual drive and orgasmic response |
| Oral Contraceptives | “The Pill” | Birth control | Various types may increase or decrease |
| Androgen Anabolic Steroids | Winstrol, Anadrol | Minimize Wasting syndrome | Increase sexual drive, change of secondary characteristics |
| Hormone Replacement Therapy | Estratest, Premarin | Adjust hormone levels post menopause | Increase sexual drive, prevent vaginal atrophy |

# Divorce and Brain Injury

- 50% of marriages and primary relationships fail within 24 months post-injury (*Burke and Weslowski, 1989*)
- Divorce/TBI rate does not exceed general divorce rate, but identifies TBI related factors
- 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

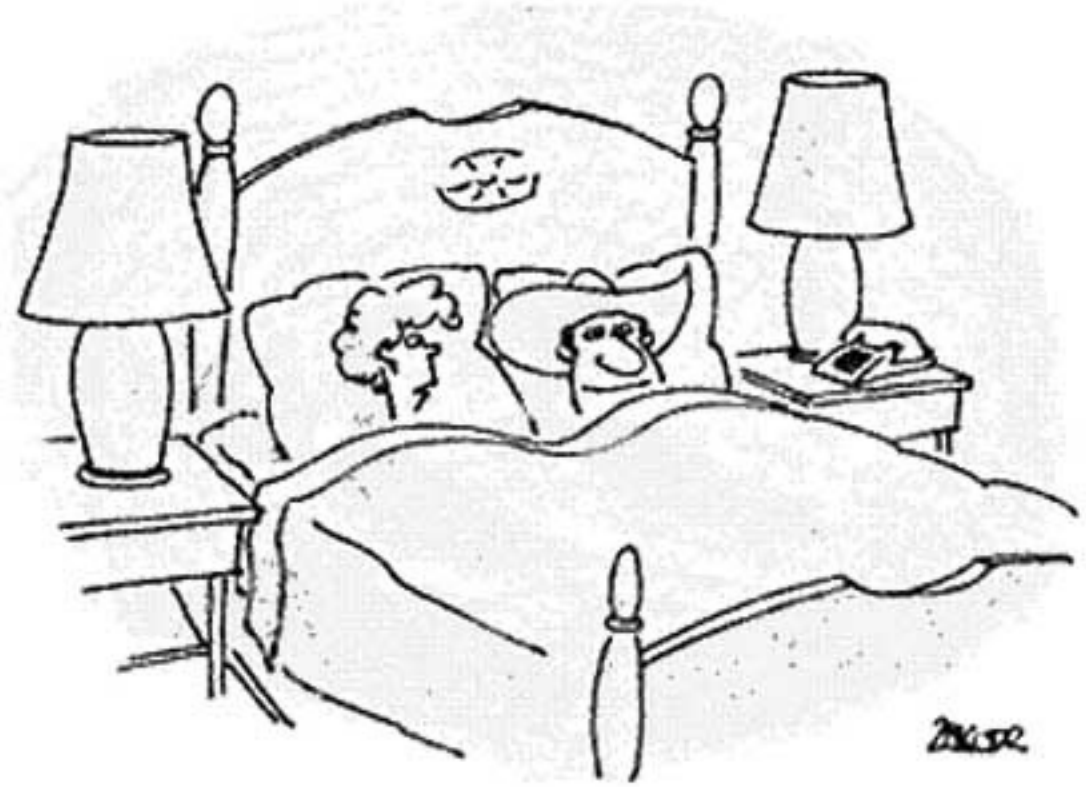
# Couples Issues

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

# Role of Compassion Fatigue in Intimacy

- Effects of stress
- Role changes for partners
- Coping with the physical, cognitive, behavioral and personality changes
- Demanding care schedule



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

# Sexuality and Brain Injury

## What are the changes which affect sexuality?

- Physical
- Cognitive
- Behavioral
- Psychological
- Social Role

# Pete and Charlene's Story: Unresolved Losses

- Loss of a child
- Loss of memory
- Loss of connection
- Loss of understanding

# Pete and Charlene's Story: Pete Imprisoned by the Past

- Grief over lost child
- Grief over loss of relationship
- Feels alone in his grief
- No longer able to communicate complex issues to wife

# Pete and Charlene's Story: Charlene Caught in the Present

- Unable to recall lost child and entire marriage
- Unable to re-assume previous role as wife
- Frustrated by lack of independence
- Confused by plans for the future.

# Cognitive Aspects of Sexuality

## Sexuality is a complex function

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

# 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

# Cal's Dating Story: From High-Energy to Hermit

- Active life as athlete
- High achiever
- Popular and sociable
- Experiences TBI
- Develops seizure disorder

# Cal's Dating Story: Post-TBI Problems

- Embarrassment of seizures
- Unable to maintain steady employment
- Social withdrawal
- Insecurity and low self-esteem

# Cal's Dating Story: Intimacy Problems

- Series of brief relationships
- Fear of rejection
- Fear of being honest
- Fear of needing support
- Efforts undermined by impulsivity and anger

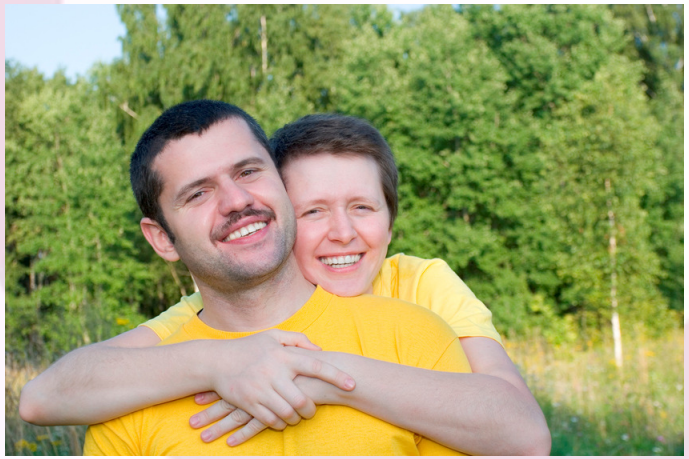
# Behavioral Changes Affecting Sexuality

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

# Initiating New Relationships

## Starting Over Issues

- Self-image/self-worth
- Learning to date
- Explaining the disability issues
- Maintaining realistic expectations for both parties
- Specific education and information



# Rob and Rose: Rob's Injury

- Car wreck leads to brain stem injury
- 3 years of intensive rehab
- Quadriplegia

# Rob and Rose: Getting back on track

- Goes back to college
- Finds job working with disabled
- Meets Rose, a therapist

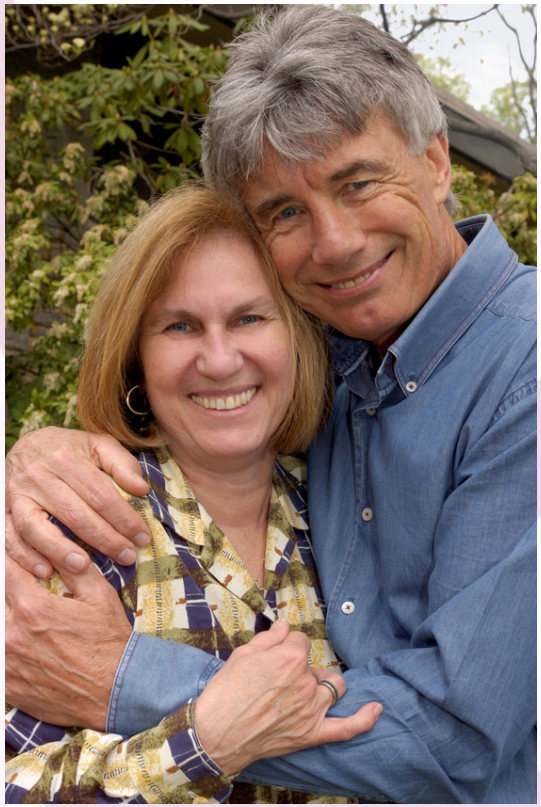
# Rob and Rose: Always a Couple

- Supportive communication
- Respect and dignity
- Open communication
- Realistic expectations

# Maintaining Former Relationships

*Coping with the changes*

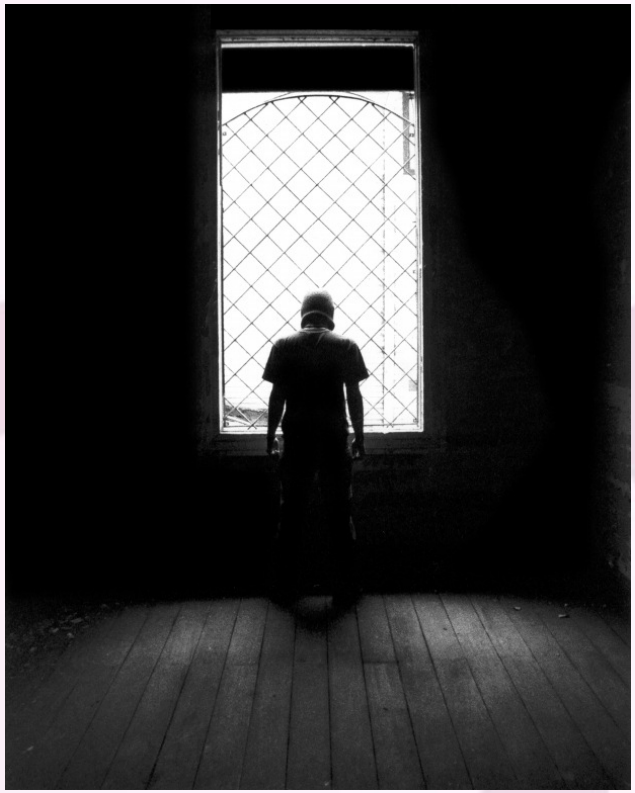
- What's old?
- What's new?
- Responding to problems
- Preventing the loss of the emotional bond
- Achieving a loving relationship



# 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

# 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)*

# Physical Changes Following Brain Injury

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

# Psychological Issues

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

# Violence and Sexual Behavior

- Impulse and anger control problems
- Individuals with history of violence more likely to become sexually aggressive post injury
- Role of memory and cognitive problems in sexual behavior

# 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

# Adding Sex to the Rehab Curriculum

- Discussing libido, intimacy, barriers to intimacy in counseling
- Address issues of sexual self-knowledge
- Identify methods to respond to physical barriers (positioning, pain)
- Assist individual to identify how a return to intimacy is part of rehabilitation and recovery

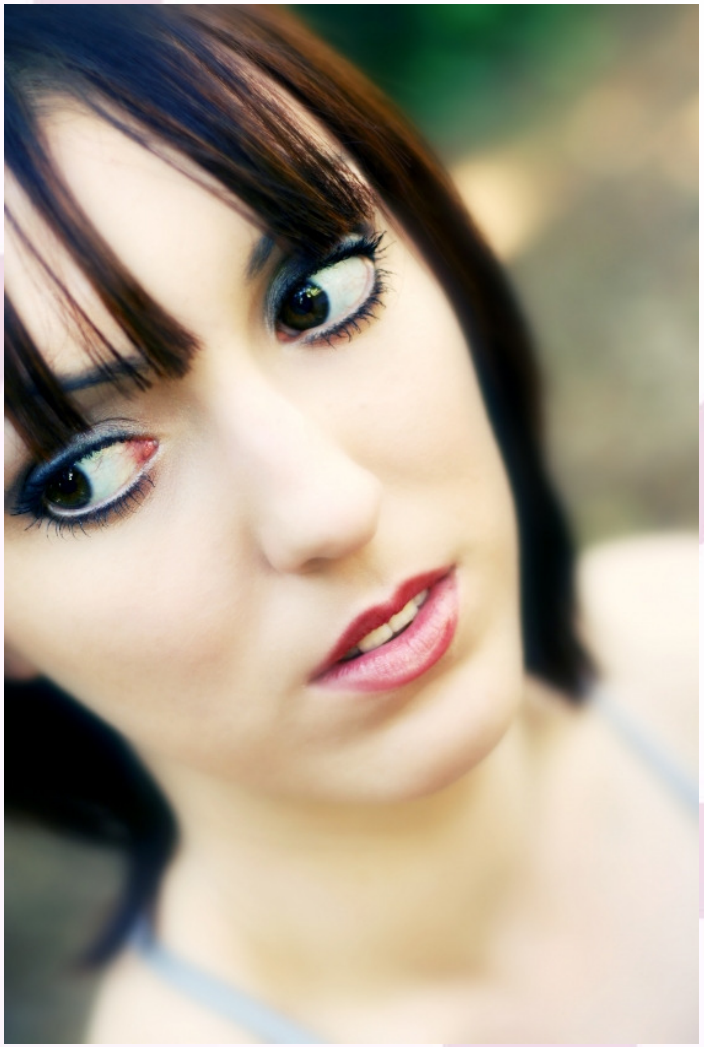
# Using Interactional "Scripts"

Creating a method for initiating and maintaining a relationship

- Conversation, sexual talk
- Negotiating time and activities
- Understanding boundaries
- The "yes" and "no" words
- Attention to cues
- Responding to another person

# Addressing Self-Regulation

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



# Treatment and Rehabilitation Implications

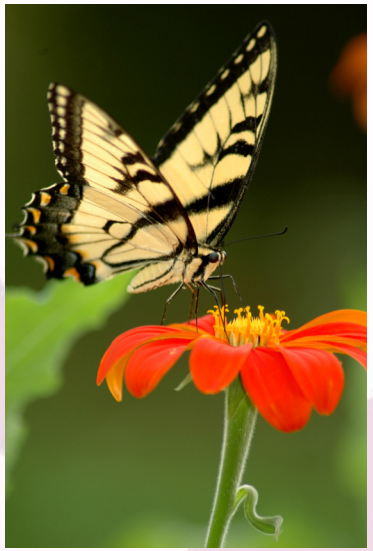
- 94% of staff in a rehab setting anticipated sexual adjustment problems if sexuality was not included in rehab. (*Hough, 1989)*
- Early incorporation of self-stimulation in the normal adaptive awakening process. (*Blackerby, 1987)*
- Education and counseling in the middle stage of recovery. (*Butler and Satz, 1988)*
- Addressing pre-morbid factors through social skills training. (*Blackerby, 1987)*
- Use of behavioral treatment to address hypersexual conduct. (*Zencius, 1990)*
- Counseling and Education; *(Zasler and Kreutzer, 1991)*

# 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 hyper-sexual 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
- Sex therapy and sexual aids
- Gay and lesbian issues

# Changing Perceptions about TBI and Sexuality

- TBI does not mean the end of sex
- Sexual needs should be addressed in both clinical and private settings
- Caregivers have sexual concerns, too

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

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