

Relationships and Intimacy After Brain Injury



Joshua Winkelman, TBI Survivor

Brooke Murtaugh, OTD, OTR/L, CBIST
Occupational Therapist
Brain Injury Program Leader
Madonna Rehabilitation Hospitals

Disclosures

- No Disclosures from either presenter.

Objectives

- Attendees will:
 - Identify impact brain injury can have on relationships.
 - Identify methods to re-establish relationships post injury.
 - Define boundaries.
 - Identify resources to assist in establishing and maintaining healthy relationships.

Brain Injury

- Brain injury can impact all aspects of the survivor's life as well as their families.



Relationships

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- Relationship defined:
- The concept of "relationships and family" is broad and varies from person to person. What you mean by relationship is unique to you, but most people do think of a state of connectedness, especially an emotional connection.
- Personal relationships refer to close connections between people, formed by emotional bonds and interactions. These bonds often grow from and are strengthened by mutual experiences.
- Relationships are not static; they are continually evolving, and to fully enjoy and benefit from them we need skills, information, inspiration, practice, and social support. In our model there are three kinds of personal relationships.

- <https://www.takingcharge.csh.umn.edu/enhance-your-wellbeing/relationships/what-do-we-mean-personal-relationships>

Intimacy

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- Intimacy defined:
 - “a close, familiar, and usually affectionate or loving personal relationship with another person or group.”



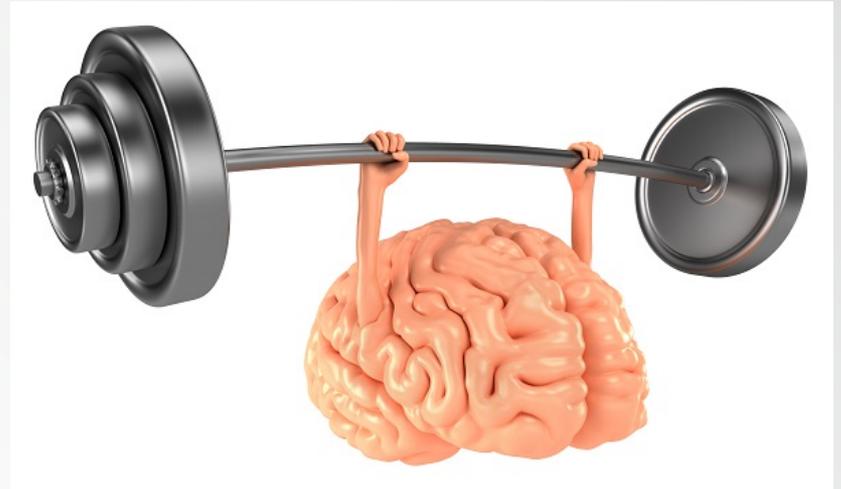
» <http://www.dictionary.com/browse/intimacy>

Why Are Relationships Important?

- *“Human beings are social creatures. We are social not just in the trivial sense that we like company, and not just in the obvious sense that we each depend on others. We are social in a more elemental way: simply to exist as a normal human being requires interaction with other people.” - [Atul Gawande](#)*

Brain Health

- A healthy brain pre and post-injury will lead to more optimal outcomes post-TBI.
- 6 Pillars
 - Physical Exercise
 - Food & Nutrition
 - Medical Health
 - Sleep and Relaxation
 - Mental Fitness
 - **Social Interaction**



Social Interactions

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- Studies have reported that healthy social relationships lead to decreased mortality rates.
- Healthy social relationships have protective effects against depression.
 - » Seeman, 2000
- A study in 2010 demonstrated that those who reported they were lonely had double the mortality rates than those with obesity.
 - » Holt-Lundstad et. Al, 2010
- Loneliness is related to cognitive decline and lower cognitive performance.
 - » Cacioppo, 2014

Relationships and Disability

- History of erroneous assumptions about individuals with disability as it relates to relationships and intimacy.
- Healthy and fulfilling relationships are crucial to achieving optimal recovery and quality of life for those with disability.

Dispel the Myths

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- Myths about disability and relationships:
 - People with disabilities always need help.
 - People with disabilities only like to spend time with others who have disabilities.
 - People with disabilities live very different lives than people without disabilities.
 - Being with a disabled person is a burden.
 - It's not possible to be with a disabled person in a relationship without any alternative motives.

Dispel the Myths

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- Myths about Disability and Intimacy:
 - Individuals with disabilities are not sexual.
 - Individuals with disabilities lack sexual desire.
 - Incapable of healthy sexual function.
 - Lack of social functioning and problem-solving
 - Sex must be spontaneous
 - Post injury, individuals are thought of to be child-like.
 - Individuals with disabilities can't control their sex drive
 - Sex is private



Brain Injury and Relationships

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- Research has demonstrated that persons with brain injury and their spouses report significant changes in their roles and marital relationship after injury.
- Factors impacting roles and relationships:
 - Communication difficulties
 - Cognitive changes
 - Behavioral and emotional changes
 - Possible change in roles of equal spouse to caregiver
 - Interpersonal skills

How Does Brain Injury Change Us?

- Physically
 - Physical changes
- Cognitive changes
 - Attention, memory, multi-tasking, executive function, safety.
- Employment changes
 - Unable to return to work, modified work, different occupation after injury.
- Emotional changes

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These changes ultimately effect
our self esteem and self identity.

Changes in Self Esteem

- Self Esteem Defined:
 - Individual's global, subjective and emotional evaluation of their perceived worth and self-acceptance as a person, which are developed and maintained by a sense of achievement and feedback from the external world.
 - » Rosenberg, 1965
 - » Guindon, 2002

Changes in Self-Esteem

- Survivors of brain injury consistently report lower self-esteem than those who have not sustained a brain injury.
- Self-conscious regarding physical and cognitive changes.
- Increased difficulty reading external social cues from others.
- Unsure of social interactions.

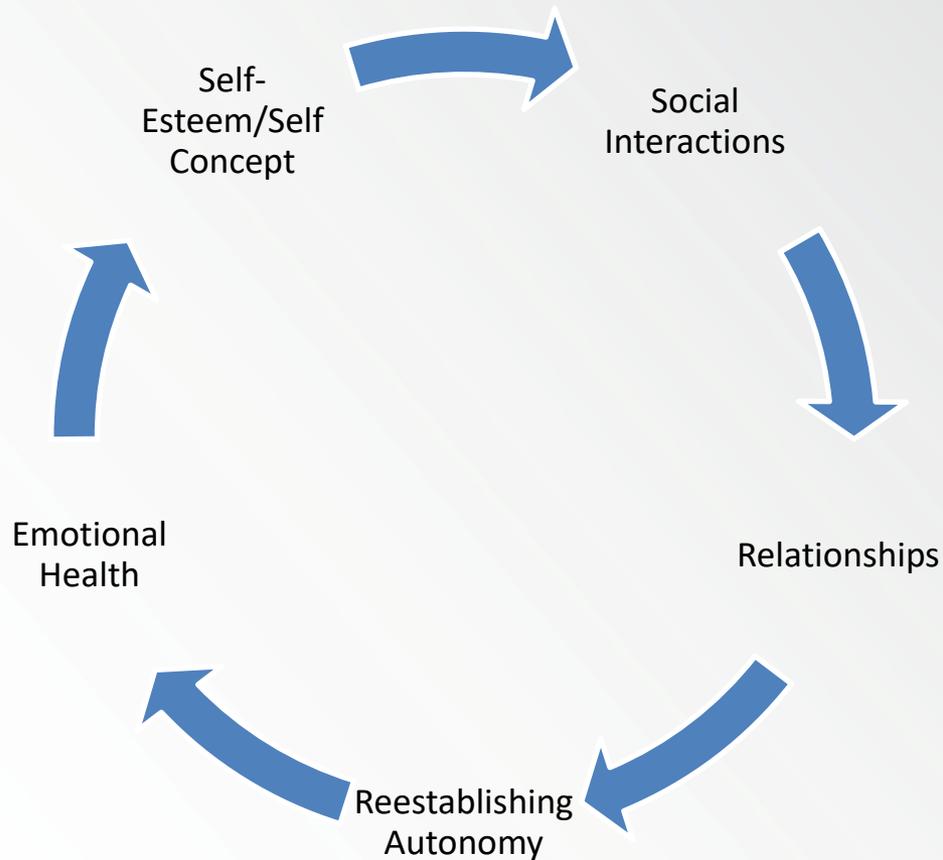
Changes in Self-Esteem

- Self-Esteem is impacted by psychological distress.
 - Depression
 - Anxiety
 - Anger issues
 - Maladaptive coping strategies
- Perceived burden of care by survivors can impact self esteem.

» Curvis, 2016

Impact of Self Esteem on Relationships

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How Does Brain Injury Impact Others?

- Sense of loss
- Change of roles
- Burden of Care
 - Caregiver burnout
- Isolation
- Loss of Social Support
- Change in employment/occupation
- Changes in emotional and physical health
 - » Carlozzi, 2015
 - » Qadeer, 2017



Relationship Changes

- 50% of marriages dissolve within 2 years of injury.
- Some studies found rates as high as 64% to 78% anywhere from 1-15 years post injury.
- Marital quality is tied to individual health and marital stability.



Relationship Changes

- Marital Quality is impacted by:
 - Negative personality traits
 - Mood swings
 - Quick Temper
 - Fatigue
 - Perceptions of communication
 - Coping Strategies

Relationship Changes

- Impact on a coupled relationship post TBI:
 - Loss of You, me, us
 - Loss of security
 - Loss of connectivity
 - Loss of future
 - Individual identity changes
 - Re-assigning of roles
 - Commitment Instability



Relationship Changes

- It is normal for the spouse/partner and person experiencing TBI to have a period of grief; mourning the loss of the relationship that once was.

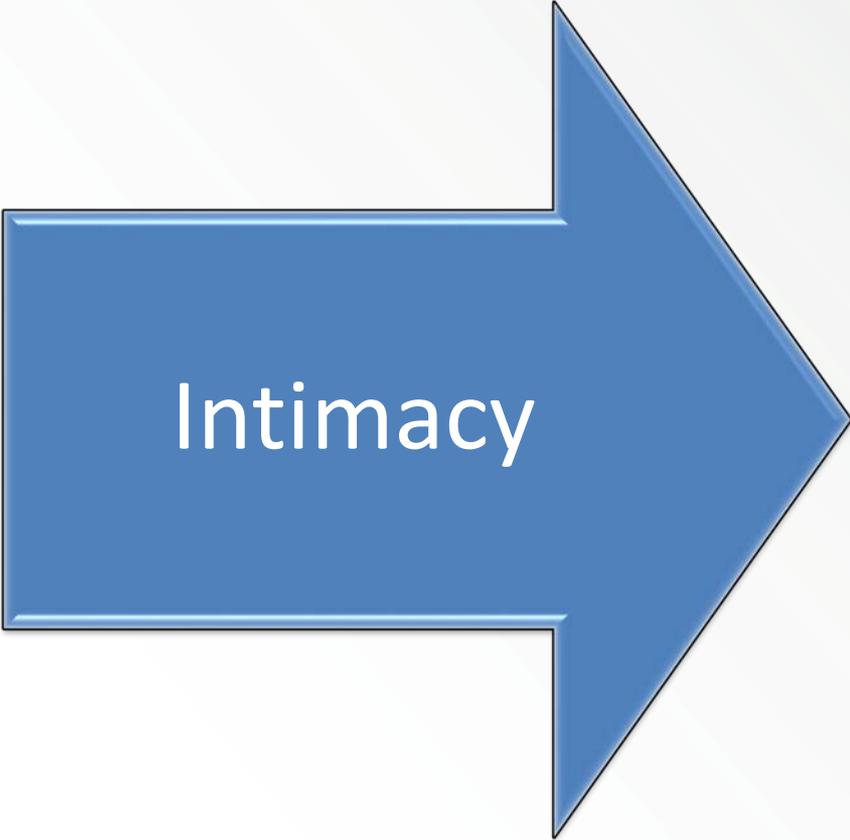


Relational Recycling

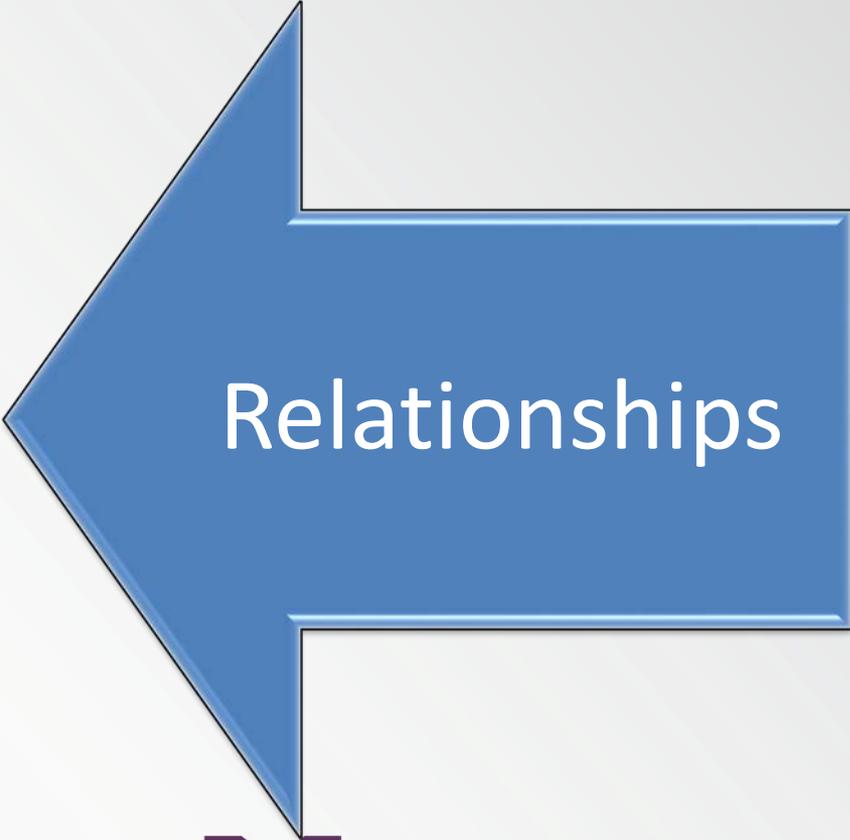
- Restructured relational identity
 - “The New Us”
- Matching of challenges with methods of rejuvenation.
- Mixing aspects of old relationship with new routines.
- Utilizing “Scripts”
- Realistic Expectations



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Intimacy



Relationships

TBI and Intimacy

- Sexuality is inaccurately portrayed as a physical phenomenon.
- Sexuality also includes personal and contextual factors:
 - Self-image
 - Desire for connectedness
 - Health issues
 - Family issues
 - Financial issues

Intimacy in 21st Century

- Modern model and concept of sexuality and intimacy include:
 - Desire to express affection
 - Share pleasurable experiences
 - Sense of being attracted and attractive
 - Sense of commitment
 - Sense of belonging
 - Sense of respect, trust, vulnerability
 - Communication

TBI & Sexuality

- Our brains control our sexuality and sexual response.
- The physical and psychological sexual responses can change after brain injury
 - Changes in desire
 - Changes in arousal
 - Inability to reach orgasm/climax
 - Reproductive changes in men and women.

TBI & Sexuality

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- Psychological changes impacting sexuality:
 - Depression
 - Anxiety
 - Altered physical image
 - Lack of self confidence
 - Social isolation
 - Fear of being rejected



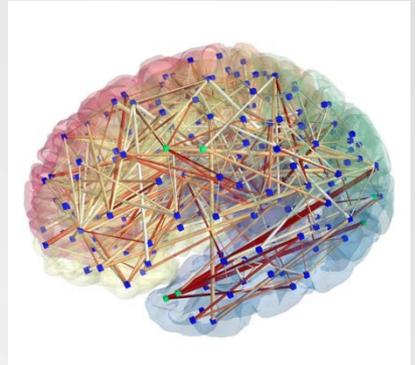
TBI & Sexuality

- Why are there physical and psychological changes?
 - Damage to the brain
 - Can change sexual arousal and response cycle
 - Hormonal changes
 - Medication side effects



Neuroendocrine Dysfunction Now You Can.®

- Sexuality can be impacted by pathophysiology of the TBI.
- Complex relationships between:
 - Brain
 - Subcortical systems
 - Neuro-chemical responses
 - Brain  Spinal Cord communication
 - Neuropsychological systems
 - Cognitive functioning



TBI & Intimacy

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- Intimacy can also be impacted by behaviors as a result of brain injury:
 - Inappropriate sexual behaviors
 - Impulsivity
 - Lack of boundaries
- How do we overcome these barriers to re-establish healthy intimacy post brain injury?

Re-establish Intimacy

- Communication
 - Survivor and spouse
 - Couple and physician
 - Couple and therapist



- Open communication is key so when help is needed, it can be provided.
- Get your questions answered.

Community Integration

- Employment, volunteerism, enjoyable community activities increases feelings of social integration and connectedness.
- These positive benefits correlate with more positive relationships with others and with increased intimacy with partners.

» Bellamkonda & Zollman, 2014

Consent

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- Intimate interactions ***must be consensual***.
- Many times the survivor's capacity for consent can be affected after brain injury.
- Evaluation is needed to assess if survivor can cognitively understand and appropriately consent to sexual relationship, even with their spouse.
- There may be a period of time where the survivor can not consent.
- Work with neuropsychology to continue to assess and establish capacity to consent.
- ***Capacity to consent/make decisions changes with context!!***
 - *Ex. Relationships vs. Money Management*

Inappropriate Behaviors

- Defined as:
 - “verbal or physical act of an explicit nature which is unacceptable within the social context in which it is carried out.”
 - » Brain Injury Medicine, 2013.
- Can result due to disinhibition
- Reduced social skills
- Poor defined boundaries



Inappropriate Behaviors

- How to manage inappropriate behaviors:
 - Stay Calm
 - Redirect sexual behavior to a private place
 - Be patient-repetition of redirection may be needed.
 - Be consistent
 - Set firm boundaries on sexual behavior
 - Seek help to find a way to have appropriate sexual expression.

Boundaries

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- Boundaries can include physical, emotional and intellectual contexts.
- Healthy boundaries promote self-esteem and self-respect.
- Facilitates equality and partnership with those around you.
- Communication and advocacy are key for establishing boundaries.



Abuse and Vulnerability

- Individuals with physical, mental and intellectual disabilities are at higher risk for abuse and exploitation.
- 4-10x more likely to become victims of violence, abuse or neglect.
- Changes in relationships can increase risk
- Males experience less than females.

Abuse and Vulnerability

- Study by Reichard, 2007, identified themes of TBI-related disabilities and experience of abuse and neglect.
 - Too passive-“let people walk all over me.”
 - Too trusting
 - Less intuitive
 - Difficulty with safety awareness
 - Drug and alcohol use

Responses to A&V

- Self-Blame
- PTSD
- Distrust
- Seeking assistance
 - Reichard 2007 study found “extremely difficult” to find help to respond or cope with Abuse and/or neglect.
- Prevention of A&V
 - Support Systems
 - Anger Management
 - Drug and alcohol prevention.
 - Increase public awareness of BI.

Social Media

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- Social Media is everywhere!
- Become a staple of society.
- Study by Baker-Sparr, 2017 found those with TBI:
 - 79% had social media account
 - 75% access social media with smart phones
 - 38% spent at least 7 hours a week on social media.
 - 44% 1-6 hours a week

Social Media

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- Increase in emotional connectedness
- Increase access to information
- Increase access and information on social and occupation-based activities.
- Resource to seek advice or help.



Social Media: Caution!

- Potential Pitfalls:
 - Excessive use
 - Can prompt feelings of envy, loneliness and depression.
 - Impulsive posts
 - Adolescents
 - On-line bullying
 - Online scams
 - Internet dating sites...

Pediatrics and Adolescents

- Relationships and intimacy are crucial parts of the discussion in regards to development after brain injury.
- Puberty!
- Dating
- Boundaries
- Peer relationships



BI Professionals

Now You Can.®

- **Clinicians responsibility to introduce the subject of intimacy and relationships.**
- Individuals with TBI want openness from care-providers to discuss subject.
- Essential to providing quality, holistic rehabilitation services.
- Study demonstrated 97% of professionals believed topic should be discussed.
- **Only 36% actually did it!!**

BI Professionals

- Lack of education and comfort in addressing the topic.
- Many institutions do not have protocols or guidelines on how to address relationships and intimacy with patients.
- How do we bridge the gap???



Bridge the Gap

- Need to develop a better understanding of problems related to relationships and intimacy.
 - What issues are impacting the survivor and significant other?
 - What issues impact the greater family unit?
 - What are the rehabilitation implications?
- Make it a priority in your Plan of Care.

BI Professionals

- Get Comfortable!!
- Get Education!
- Program Development
 - Get organized and get support
 - Consistency
- Interdisciplinary
- PLISSIT Model



PLISSIT Model

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- Structured was to address relationships and intimacy.
 - **P-Permission**
 - **LI-Limited Information**
 - **SS-Specific Suggestions**
 - **IT-Intensive Therapy**
- Includes open-ended questions, factual information, information on problem solving, and individualized treatment.

Relationship Resources

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- BIAA-NE
- Brain Injury Association of America
- TBI Model Systems
 - www.msktc.org
- Seek referrals from trusted providers
 - Psychiatry
 - PCP
 - Psychology

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Questions?

bmurtaugh@madonna.org



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