Addressing Sexual Health After Brain Injury

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HEADS UP WEBINAR SERIES

Disclosures

Information provided in this presentation has been adapted from presentations formerly given by Devin Pino, OTS, and Dr. Sheryl Berardinelli, PsyD, ABPP.

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Following This Session:

You should be able to:

- Discover changes in sexual functioning, intimacy and relationships faced by individuals with brain injury
- Explain the role of rehabilitation team members in supporting the sexual health and basic rights of their clients
- Describe assessment and treatment strategies to promote sexual health after a brain injury

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Definitions

- Sexual Health
- Brain Injury
- Sexual Rights
- Sexual Consent Capacity
- Sexual Dysfunction

Sexual Health

According to the current working definition, **sexual health** means:

- "…a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." *(WHO, 2006a)*

Brain Injury

According to the definition provided by the Brain Injury Association of America *(BIAUSA)*, **acquired brain injury** means:

- "…an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma… The injury results in a change to the brain's neuronal activity, which affects the physical integrity, metabolic activity, or functional ability of nerve cells in the brain." *(BIAUSA.org)*
- An acquired brain injury may be traumatic (fall, assault, motor vehicle accident, etc) or non-traumatic (stroke, seizures, tumor, etc).

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Sexual Rights

According to the current working definition, **sexual rights** means:

"The application of existing human rights to sexuality and sexual health… Sexual rights protect all people's rights to fulfil and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination." *(WHO, 2006a, updated 2010)*

Human rights critical to the realization of sexual health include:

- The rights to equality and non-discrimination
- The right to privacy
- The right to decide the number and spacing of one's children
- The rights to information, as well as education
- The rights to freedom of opinion and expression

Sexual Consent Capacity

Sexual consent capacity has been defined as "the ability to voluntarily make a reasoned decision whether or not to engage in sexual activities." *(Syme & Steele, 2016)*

Capacity to consent has been further described, by Lyden (2007), as "An adult person has sexual consent capacity if the requisite rationality, knowledge, and voluntariness are present."

Sexual Dysfunction

The 4 main areas of sexual dysfunction are:

- Sexual desire disorders
- Sexual arousal disorders
- Orgasmic disorders
- Sexual pain disorders

According to the definition provided by the Cleveland Clinic, **sexual dysfunction** means:

"A problem that can happen during any phase of the sexual response cycle."

(Sexual Dysfunction, 2020)

Human Sexual Response

Typical Reaction Pattern

- **Desire**
  - Sex drive, sexual need
  - Experience a desire for sexual activity before it happens
- **Arousal/Excitement**
  - Physical changes occur to prepare body for sexual activity (increased heart rate, changes in breathing, increased muscle tension, increased blood flow, erection/lubrication)
- **Plateau**
  - Sexual activity is occurring, physical changes become more intense
- **Orgasm/Climax**
  - Release of sexual tension
- **Resolution**
  - "Quiet" phase following orgasm/climax
  - Body returns to its normal state

Effects of Brain Injury on Human Sexual Response

Possible Impact of Brain Injury on Reaction Pattern

- **Desire**
  - Decreased desire
  - Increased desire, fixation
- **Arousal/Excitement**
  - Decreased arousal
  - Erectile dysfunction
  - Insufficient lubrication
- **Plateau**
  - Physical inability to achieve or maintain positions
  - Limited endurance
  - Limited attention
- **Orgasm/Climax**
  - Difficulty or inability achieving orgasm
- **Resolution**
  - Delayed calming

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Physiological Changes

Changes in Body Functions

- According to a study by Goldin, et al., approximately 30-50% of individuals diagnosed with a traumatic brain injury experience difficulty with sexual functioning. (*Goldin et al., 2014*)

  Causes of physiological changes and sexual dysfunction may include:

  - Injury to various parts of the brain
  - Neurochemical & hormonal changes
  - Fatigue
  - Medication effects
  - Psychological factors
  - Cognitive decline
  - Sleep-wake cycle disturbances

- Physiological changes will depend on areas impacted by brain injury.
  - Limitations will require unique solutions to common problems

Physiological Changes

Effects of Brain Injury on Sexual Functioning

- Brain stem: disruption of information flow regarding sexually-relevant information.
- Basal hypothalamus: irreversible loss of libido
- Temporal lobe: decreased libido, genital and sexual arousal
- Hypothalamus and limbic structures: hypogonadism (endocrine disorder) and hyposexuality (decreased desire)
- Frontal lobes: disinhibition, sexually inappropriate behaviors, difficulties with arousal, impaired initiation, attention difficulties, disrupted ability to fantasize, difficulties with orgasm.
- Dominant hemisphere: communication difficulties, impaired motor performance, depression, decreased libido
- Non-dominant hemisphere: impulsivity, lack of awareness, difficulty orienting body due to visual-spatial difficulties, difficulty interpreting and expressing nonverbal cues and emotional aspects of communication.

Physiological Changes

Physical Ability & Body Functions

Following brain injury, disruptions in intimacy and ability to satisfy sexual needs can be caused by various physical changes.

- Erectile dysfunction
- Diminished or heightened sensation
- Inability to control bowel and/or bladder
- Temperature dysregulation
- Headaches
- Endocrine dysfunction
- Limited stamina
- Coordination impairments
- Decreased flexibility
- Limited strength
- Increased or decreased tone

(Yang et al, 2018)

Physiological Changes

Cognition

Post-brain injury changes in cognition and processing may limit an individual's ability to navigate both novel and familiar situations.

- Impaired memory
- Limited prospective planning skills
- Decreased attention span

Communication

Expressive and receptive language, along with social pragmatic skills, may be altered following an acquired brain injury.

- Impaired expression and ability to clearly communicate
- Impaired comprehension and ability to understand others
- Limited social interaction skills

Physiological Changes

Psychological Function

Psychological changes can impact the way an individual views themselves, others, or situations they encounter.

- Mood swings
- Change in self-esteem
- Depression
- Personality changes
- Feelings of isolation

Behavior

Limited self-regulation is commonly noted following brain injury.

- Impulsivity
- Limited self-monitoring and awareness of impact of actions
- Flattened affect
- Delayed reactions

Impact of Brain Injury

Effects on Relationships

Following brain injury, many experience disruption in relationship dynamics due to:

- Decreased social engagement
- Changes in roles and responsibilities
- Emotional and personality changes
- Caregiver stress
- Limited time and energy
- Changes in perception of sex appeal
- Fear over injury
- Caregiver's emotional or psychological reaction to their loved one's brain injury

Research has indicated that dependence in activities of daily living (ADLs) increases the risk of sexual disorders *(Zarreii et al., 2011)*.

Impact of Brain Injury

Gender Differences

A study by Hibbard et al (2000) identified that there are significant gender differences regarding impact of brain injury of sexualy functioning.

- Women:
  - Sexual problems - 2-3 compared to 0-1 in non-injury population
- Men:
  - Relationship Status - <50% compared to ~75% in non-injury population
  - Frequency - ~50% compared to 85% in non-injury population engaging in past year
- Common Factors:
  - Age at time of injury
    - Older = more dysfunction
  - Psychological status
    - Depression was consistently correlated with lower satisfaction levels

(Hibbard, et al., 2000)

Why Address Sexual Health?

Healthcare & Rehabilitation Professionals

What if we ignore sexual health in rehab?

Negative results of sexual needs going unmet may include:

- Impulsive behaviors
- Inappropriate verbal expression of desires towards others
- Inappropriate actions towards others
- Fractured relationships
- Physical discomfort
- Engagement in unsafe sexual practices
- Emotional dysregulation, agitation or frustration
- Increased stress

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Why Address Sexual Health?

Benefits of Addressing ¨The Forgotten ADL¨

- Increasing self-esteem
- Improving quality of life
- Supporting engagement in consensual or personal acts may limit frustration and improve behavior
- Developing comfort in discussing sexual health may increase client willingness to seek solutions
- Improving self-awareness for greater willingness and ability to participate in intervention to support needs *(Dombrowski et al., 2000).*

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What is Our Role?

Healthcare & Rehabilitation Professionals

Our role is to support the rights, health and wellbeing of our clients, including:

- Engagement in intimate relationships
- Participation in self-expression
- Performance of all self-care acts

Providing holistic healthcare services requires consideration of the client's physical, emotional, social, spiritual and economic needs along with their response to illness and the effect of their illness on ability to meet self-care needs. *(Ventegodt et al., 2016)*

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What is Our Role?

Healthcare & Rehabilitation Professionals

Responsibilities include:

- Supporting Human Rights
- Understanding post-brain injury difficulties and expression of sexuality
- Clarifying personal values
- Developing rapport and communication skills
- Assessing capacity for sexual consent
- Educating clients to promote informed decision-making

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Where Do We Fall Short?

Healthcare & Rehabilitation Professionals

In most healthcare settings, professionals are not addressing sex, intimacy, and personal relationships.

- A study by Arango-Lasprilla et al. (2017) reviewed the level of training and attitude of various health-care professionals (n=324) on working with TBI patients and guidelines related to sexual issues.

- Findings indicated that healthcare professionals agreed that they:
  - Should encourage/support sexual activity in adults with TB
    - 97% endorse sexuality as a topic to be discussed
    - However, only 36% report discussing sexuality with their patients
  - Lack of training
    - 29% discussing it only AFTER the patient brought it up

Why Do We Fall Short?

Healthcare & Rehabilitation Professionals

Why do we fall short?

- Lack of training
- Personal bias
- Inaccurate beliefs
  - Belief that patients and their loved ones are not comfortable talking about these topics
  - Belief that addressing sexual health is outside of our scope

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What Do Our Clients Say?

Individuals with TBI reported *low frequency* of discussions with their treating clinicians regarding:

- Contraception: 69.4%
- Desire to have children: 83.3%
- Problems with condom use: 86.5%
- Safer sex practices: 88.9%
- Sexual problems: 72.2%
- Communication about sexuality 72.2%
- HIV prevention: 83.3%
- STD prevention: 64.9%
- Side effects of drugs on sexuality: 72.2%

(Moreno, et al., Neurorehabil; 2015)

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How Do We Develop Proficiency?

Developing Knowledge & Skills to Better Address Sexual Health

- Rehabilitation staff need to be proficient in discussing sexual concerns with patients.
  - Gain better understanding of post-brain injury difficulties and expression of sexuality
  - Clarify personal values
  - Develop rapport and communication skills
  - Educate on interventions to support sexual health and engagement
  - Initiate addressing sexual health in treatment, when appropriate

Addressing Sexual Health

Open the Conversation

Rehabilitation professionals have a duty to treat the "whole patient" - including addressing sexual health.

Who Can Approach the Topic? -- ANYONE!

Tips for Professionals:

- Keep it professional
- Use technical/formal language
- Allow for the patient to express their issues in a judgment free way
- Provide resources
- Refer out if needed

(Headway, 2017)

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Addressing Sexual Health

Assessments

- Psychosexual Assessment Questionnaire
- Sexual Interest and Satisfaction Scale
- Derogatis Interview for Sexual Function - Self Report
- Brain Injury Sexuality Questionnaire - developed and validated specifically for TBI

EX-PLISSIT Model

Modeling system created by Sally Davis and Bridget Taylor in 2006 used in the field of sexology to determine the different levels of intervention for clients. It is helpful in meeting the sexuality and sexual healthcare needs of patients.

- Places permission-giving at the core of each stage.

EX-PLISSIT Model

Permission Giving Stage

- First step in addressing the patient's sexual health needs
- Provides patients with the opportunity to voice their concerns
- Gives the patient permission to feel comfortable about a topic or permission to change their lifestyle or to get medical assistance.
- The clinician is a nonjudgmental listening partner, allowing the patient to discuss matters that would otherwise be too embarrassing for the individual to discuss.

Example: "People with brain injuries often experience sexual difficulties, such as loss of desire or problems with enjoyment. How have you been affected?"

EX-PLISSIT Model

Limited Information Stage

- The patient is supplied with limited and specific information on the topics of discussion.
- Information about the impact of injury/disability on sexuality and the effects of treatments on sexual functioning should be discussed.
- Clinicians have the important role of clarifying misinformation, dispelling myths, and giving factual information in a limited manner.

EX-PLISSIT Model

Specific Suggestions

- Clinician gives the patient suggestions related to the specific situations and assignments to do in order to help the patient fix the mental or health problem.
- May include suggestions how to deal with sex-related infections or information on how to better acheive sexual satisfaction by the patient changing their sexual behavior.

Examples:

- Hemiplegia: affected persons to lie either on back or side with the unaffected side uppermost.
- Difficult arthritic stiffness and pain: experiment with different sexual positions and taking pain relievers before sexual activity
- Muscle spasms interfering with intercourse: try different sexual positions
- Discomfort or pain in intercourse: use of lubricants and consider full range of sexual activities.

EX-PLISSIT Model

Intensive Therapy Stage

- Refer the patient to other mental and medical health professionals that can help them deal with the deeper, underlying issues and concerns being expressed
- Referral to sexual dysfunction clinics, psychosexual counseling, sex therapists, sex surrogate therapy

- Reasons to refer:
  - If the issue is beyond your competence
  - Rape or sexual abuse
  - Relationship problems that warrant marriage/couples counseling

Goal Areas

Goals may come from several resources on a rehabilitation team based off evaluations and assessments completed.

The following goals are examples provided by licensed clinicians from our Bancroft NeuroRehab's program.

Goals may vary depending on the specific needs of the individual.

Psychology Goals

Examples:

Patient will be able to engage in healthy and safe dating practices and be able to verbalize them twice per month.

Patient will accept personal responsibility for their own behaviors utilizing "I statements" weekly for 4 consecutive weeks.

Patient will engage in social skill building sessions once per week.

Physical Therapy Goals

Examples:

Patient will increase 5x sit-to-stand score by 5 seconds closer to age-related norms to demonstrate increased LB strength and stability.

Patient will follow HEP from printed handout with family training completed as needed.

Patient will perform bed mobility required for independence in sexual activity with Min(A) for safety and stability.

Occupational Therapy Goals

Examples:

Following education, patient will demonstrate working knowledge of AE for increased participation in sexual activity 4/5 trials.

To increase safety and independence in ADLs, patient will ID and implement two energy conservation strategies with less than 3 verbal cues from therapist.

To demonstrate safe engagement in ADLs/IADLs, patient will tolerate 20 minutes of dynamic functional activity from sitting position, utilizing energy conservation strategies as needed.

Speech Therapy Goals

Examples:

Patient will improve vital capacity by sustaining /ah/ for 10 seconds at 70dB or greater

Patient will identify appropriate/inappropriate behaviors in themselves and others 7/10 opportunities.

Patient will modify behavior based on actions of others 7/10 opportunities.

Improving Sexual Functioning and Satisfaction

General Suggestions:

- Get a comprehensive medical examination
- Arranging a non-distracting environment
- Minimizing fatigue/tiredness
- Compensating for memory problems
- Compensating for decreased ability to fantasize or imagine sex
- Compensating for erectile dysfunction
- Compensating for female sexual difficulties
- Psychotherapy
- Treatment to improve social communication skills
- Sex therapy
- Increase opportunities for social interaction
- Alternative sexual behaviors

(Sander et al., 2011)

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Improving Sexual Functioning and Satisfaction

Recommendations

Examples of recommendations made following assessment may include:

- Positioning Aids
  - Wedges, pillows, wheelchair
- Adaptive Equipment
  - Compensate for limited hand function, strength, flexibility
  - Modifications may be required to off-the-shelf items to accommodate physical limitations.
  - Training may be required to support the safe and effective use of such products
    - I.e.: hygiene, set up of equipment

Improving Sexual Functioning and Satisfaction

Recommendations

Examples of recommendations made following assessment may include:

- Compensation strategies
  - Energy conservation
  - Memory
  - Attention
- Remediation
  - Refers to the restoration of "skills such as ROM, strength, endurance, effective communication and social engagement as part of meeting sexual needs."
    - Increasing strength and ROM to improve ability to bear weight through the upper extremities
    - Simulate social scenarios to reduce anxiety during social situations

(Mohammed, 2017)

Rights in Sexuality and Relationships

- Individuals with BI have the same rights as other people to engage in sexual activities and to be sexually fulfilled.
- Some people with BI are more vulnerable to harm by others, as a result of physical limitations or decreased cognitive abilities.
- People have the right to have their sexual needs and preferences accepted and treated with respect.
- People have the right of privacy and confidentiality in all aspects of their lives including their personal relationships.
- People have the right to stop having sex with someone at any time.

(Simpson, 2003)

Rights in Sexuality and Relationships (Cont'd)

- People have the right to get information that they can understand about:
  - Social relationships and communication skills
  - Sexual matters, such as contraception, masturbation, sexual hygiene, pregnancy and prevention of sexually transmitted infections
  - Social and legal responsibilities regarding sexual relationships
  - Ways of avoiding sexual exploitation and abuse
- People have the right to say no to things that other people do that make them feel uncomfortable or upset, physically and sexually.

(Simpson, 2003)

Laws, Regulations and Ethical Codes

NY State Office of Mental Retardation and Developmental Disabilities Commissioner's Memorandum states that "a parent, a legal guardian, or a committee cannot limit an adult person's sexual activity.

In Griswold vs. Connecticut (1965), the US Supreme Court affirmed that every person has the right to privacy, to certain forms of sexual conduct, and to make reproductive decisions.

The National Guardianship Association's Standards of Practice indicated that a "guardian shall acknowledge the ward's right to interpersonal relationships and sexual expression."

American Association on Intellectual and Developmental Disabilities asserts that "people with mental retardation and related developmental disabilities, like all people, have inherent sexual rights and basic human needs. These rights and needs must be affirmed, defended and respected."

Sexual Consent Capacity

Capacity is a *state* and not a *trait.* It can vary over time.

- **How does the law define the boundaries of sexual behaviors?**
  - "Any touching of the sexual or other intimate parts of a person not married to the actor for the purpose of gratifying sexual desire of either party" (NY Criminal Law Statues, Penal Law Section 130, 1997)
- **NY uses a "morality standard"**
  - A person must be mentally capable of understanding the social mores of sexual behavior.
  - A person must be capable of understanding the non-criminal penalties (ie: ostracism, stigmatization) that society may impose for conduct it labels as sexually immoral.
- **NJ has one of the least restrictive legal standards.**
  - Only requires that a person must understand the sexual nature of an act and that the person's decision to engage in sexual behavior is voluntary.

Sexual Consent Capacity

Suggested criteria for inferring sexual consent capactiy *(Ames & Samowitz, 1995)*

- Voluntariness
- Safety
- No exploitation
- No abuse
- Ability to say “no”
- Socially appropriate time and place

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Sexual Consent Capacity

Assessment

- Rationality: Ability to critically evaluate, to weigh the pros and cons, and to make a knowledgeable decision.
- Knowledge
  - Knowing the specific sexual behaviors in question
  - Choice to accept or reject the sexual behaviors in question
  - Illegality and unpleasant consequences of various specific sexual behaviors
  - Pregnancy and sexually transmitted infections prevention
  - Social and legal constraints on time, place, and context
  - Physical, legal, and ethical responsibilities associated with pregnancy and parenting
- Voluntariness: Person must be able to take self-protective measures against unwanted intrusions, abuse, and exploitation

Disability & Sexuality Health Care Competency Model

Developing a Sexual Health Program

- Disability & Sexuality Critical Awareness
- Disability & Sexuality Knowledge
- Disability & Sexuality Skills
- Disability & Sexuality Practice and Application (Disability)
- Disability & Sexuality Practice and Application (Sexuality)

(Mona, et al. 2017)

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Sexual Health Programming

Disability & Sexuality Critical Awareness

- Providers engage in self-assessment of personal beliefs about the disability experience
- Providers become aware of our biases about disability & sexuality
- Take a critical eye to policies and procedures currently in place in practice settings
- Understand disability from client's perspective
- Learn about physical, cognitive, and social aspects of disability
- Seek basic knowledge of sexual anatomy and function, normative sexual arousal and response cycles, common sexual concerns, etc.

Sexual Health Programming

Disability & Sexuality Knowledge

- Initiate conversation about sexuality and allow time to explore the topic
- Include sexual health in clinical assessment and routinely evaluate your own disability and sexuality implicit bias
- Match the language used by the patient to establish and maintain rapport

Disability & Sexuality Skills Development

- Participate in professional activities relevant to the fields of disability studies and sexual health
- increase competence in conceptualizing assessment results from a disability-affirming perspective

Disability & Sexuality Practice and Application

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Sexual Health Programming

Example of Sexual Health Manual

- **Purpose**
  - To provide the individuals we support and staff members with **essential information and guidance** for the expression of sexuality and in the development of fulfilling social relationships consistent with developmental level, cognitive ability, emotional maturity, interests, and moral beliefs of individuals we support.
- **Application**
  - This manual provides information and guidelines to all Bancroft staff as part of the services provided to individuals supported by Bancroft.
  - This manual will also serve as a resource for parents, guardians and other stakeholders.

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Sexual Health Programming

Example of Sexual Health Manual, continued

- **Sexual Consent**
  - Bancroft's Social-Sexual Manual (pg. 22-23) indicates that individuals are able give informed consent to sexual intercourse when:
    1. The individuals involved are consenting adults.
    2. If deemed necessary, they have been assessed by the appropriate clinical staff and deemed able to give consent.
    3. They meet minimum age as defined by state law (as legal prohibition varies across states).
    4. They have demonstrated an understanding of privacy, respecting the rights of others, individual consent, and safer sex practices.
    5. Activity is conducted in private and does not infringe on the rights of others.

Sexual Health Programming

Example of Sexual Health Programming

- **Social-Sexual Advisory Committee**
  - Serves as a **resource** for staff, individuals supported, families, guardians, and stakeholders with regard to social/sexual topics relating to individuals supported.
    - Composed of representatives from different service lines and disciplines within the organization.
    - Reviews the organization's Social-Sexual Manual annually and revisions will be disseminated to program leadership.

Main Takeaways

- Sexual health following acquired brain injury is an under-approached topic in rehabilitation due to lack of provider´s lack of knowledge, limited comfort, and personal biases, leaving clients underserved.
- There are several physiological, sociological, psychological, and circumstantial factors that may contribute to sexual dysfunction and unmet sexual needs for individuals who have experienced acquired brain injuries.
- Rehabilitation team members have a duty to address sexual health for all clients in order to uphold their rights.
- Professionals must seek avenues to become more comfortable/willing to initiate sexual health conversations with those in their care.
- Assessments and models are available to support healthcare professionals in addressing sexual health with their clients.

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More Information

Resources for Client Education:

- National Institute on Disability and Rehabilitation Research (https://www.nidcd.nih.gov/)
  - Sexual Functioning and Satisfaction after Traumatic Brain Injury: An Educational Manual (pdf)
  - Addressing Sexuality in Traumatic Brain Injury Rehabilitation: A Guide for Rehabilitation Professionals (pdf)

Resources for Devices & Aids:

- Supportive Positioning for Sexual Activity https://onf.org/wp-content/uploads/2019/08/2.-Handout-Supportive-Positioning-for-Sexual-Activity.pdf
- Adaptive Equipment

  https://icord.org/wp-content/uploads/2019/09/PleasureABLE-Sexual-Device-Manual-for-PWD.pdf

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Questions?

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Thank you!

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