

Sex & Intimacy After Brain Injury: Strategies for Communication and Participation

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Presentation Outline



- **Overview of sex & intimacy**
 - Definitions
 - Importance
 - Experiences of survivors and partners
 - Impact of societal views
- **Professional support**
 - Why sexual intimacy goes unaddressed
 - How it can be addressed
- **Physical symptoms of ABI that can impact participation**
 - Treatment options
 - Assistive devices
- **Cognitive, emotional, and role changes after ABI that can impact participation**
 - Treatment/support options
 - Strategies to increase communication
- **Q&A/Discussion**

Objectives

- Articulate the difference between sexual activity and sexual intimacy
- List three symptoms of ABI that can impact participation in intimacy and a strategy or assistive device to address each
- Identify an evidence-based model for addressing sex and intimacy in health care and counseling settings



Overview of Sex & Intimacy

*Definitions, Importance, Survivor & Partner
Experiences, Societal Views*



Intimacy & Sexual Activity: What's the difference?

- **Intimacy** - generally, a closeness and comfortability that can take on many forms, including: emotional, intellectual, physical, and...
 - **Sexual intimacy** - involvement in an interpersonal and/or sexual relationship with another person in which positive emotional connections and a commitment have been established (*Gill, et. al., 2011*)
- **Sexual Activity** - “Engaging in the broad possibilities for sexual expression and experiences with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse) (*AOTA, 2020*)

Why Are Sex & Intimacy Important?

- Sexual activity is considered an **Activity of Daily Living (ADL)** (AOTA, 2020)
- **Relationships:** a correlation exists between sexual and relationship satisfaction (Yoo, et. al., 2014)
- A satisfying romantic relationship supports both partners' **quality of life** and **health status** (Fraser, et. al., 2020)



Why Are Sex & Intimacy Important?

- **Self-expression:** sexuality is closely related to one's identity (*Kaufman, et.al., 2007*)
- **Mental health:** individuals with chronic impairments often rate lower on scales that examine sexual self-esteem and satisfaction (*Moin, et. al., 2009*)
- **Physical health:** reproduction, physical activity, hormone release (dopamine, serotonin, oxytocin, etc.)



Experiences of Survivors

A brain injury can impact an individual's sex life in a number of ways, and survivors may experience:

- Being unsure if sex or masturbation is safe or possible, especially not knowing what support or strategies may help
- Changes in the sexual dynamics of their existing relationship that lead to feelings of frustration, guilt, self-consciousness or disappointment
- If single, a survivor may question if they will be able to attain a satisfying romantic relationship in the future



Experiences of Partners

A brain injury can impact a couple's sex life in a number of ways, and **partners** may experience:

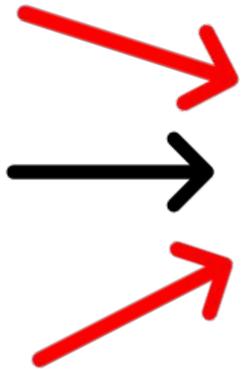
- Being unsure if sex is safe or possible, especially not knowing what support or strategies may help
- Changes in the sexual dynamics of their existing relationship that lead to feelings of frustration, guilt, self-consciousness or disappointment



Impact of Misinformed Societal Views

- Society often does not recognize people with disabilities as sexual beings.
- People with disabilities often report feeling like they are not viewed as attractive or suitable sexual partners by people without disabilities.

(Kaufman, et. al., 2007)



BUT the truth is – people with disabilities, including brain injuries, are no different than their peers without disabilities in their interest and need for sexual expression

Professional Support

*Reasons unaddressed, how to address,
where to seek support*



Why Do Sex & Intimacy Go Unaddressed?

- The rehabilitation process and medical professionals involved in this process **often leave little room** to the discussion of sexual functioning (*Grenier-Genest et al., 2017*)
 - Time constraints, priorities at different stages
- In part due to practitioners having received **minimal training** on how to address sexual issues (*Schmitz & Finkelstein, 2010*)



Why Do Sex & Intimacy Go Unaddressed?



- An **intimidating topic** for many to raise, despite the fact that individuals recovering from stroke “have voiced the need to address the issue of post-stroke sexual functioning during rehabilitation” (*Grenier-Genest, et. al., 2017*)

How To Address: The PLISSIT Model

The **PLISSIT model** (created by Dr. Jack S. Annon) has four stages:

1) **P: Permission**

Mention sex and intimacy while discussing the potential implications of an individual's diagnosis or treatment. Give the client permission to think about and discuss concerns related to sexual health within the treatment process.

2) **Li: Limited Information**

Begin by giving the client limited information about the impacts that their diagnosis or treatment might have on their sexuality.

The PLISSIT Model (Continued)

3) SS: **Specific Suggestions**

Make specific suggestions about problems that the client has encountered.

4) IT: **Intensive Therapy**

If you feel as though the client could benefit from intensive therapy relating to their sexual health, refer them to a professional with expertise in that area.

The EX-PLISSIT Model

- Some health-care professionals advocate using an extended PLISSIT model (EX-PLISSIT).
- The extended PLISSIT model **emphasizes explicit permission-giving** as being an important component of **all stages** of discussing sexual well-being. Limited information, specific suggestions, and intensive therapy do need to be addressed sequentially, but can overlap during the therapeutic process.

(Taylor & Davis, 2014)

Survivor/Partner: How to bring it up with a provider



- Talk to your doctor, nurse practitioner, or therapist – ask for a referral to a specialist if they can't address your needs
 - www.aasect.org has directory of sex therapists and counselors
- If you are working with outpatient therapy, ask if there is someone on the team who specializes in sexual rehabilitation

Survivor/Partner: How to bring it up with a provider

- Look up specialists in your area or that provide telehealth, may include:
 - Neuropsychologist
 - Sex therapist
 - Pelvic floor therapists
(typically an occupational or physical therapist)
 - Couples counselors
- It may take extra research, but it's worth it! Don't give up!

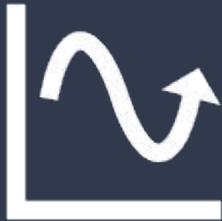


Physical Symptoms of ABI That May Impact Participation in Sex and Intimacy

*Overview, treatment options,
assistive devices*



Physical Symptoms That May Impact Sexual Participation



- **Balance issues, dizziness**
- **Fatigue**
- **Pain**
- **Incontinence**
- **Weakness or paralysis, hemiparesis**
 - Gross motor
 - Fine motor
- **Limited mobility**
- **Changes in sensation**
 - Hyposensitivity
 - Hypersensitivity
- **Seizures**
- **Hormonal changes**
- **Changes in the sexual response cycle**
- **Medication side effects**

Treatment Options

- **A comprehensive medical exam**
 - Be sure to tell your doctor about any sexual difficulties or other health problems that you are having.
 - If you are having difficulty with your sex drive, physical arousal (including erections), or achieving orgasm, it is worth speaking with your PCP to see if they have any medical recommendations such as medications.
- A **pelvic floor therapist** may also be able to help if you are experiencing pain during sex, incontinence, or erectile dysfunction.

Helpful Strategies

- **Fatigue**

- Energy conservation techniques – consider comfortable positioning, pace, mini-breaks, can one partner self-pleasure before the other joins in?
- Timing – when do you have the most energy? Schedule when you have time to rest after

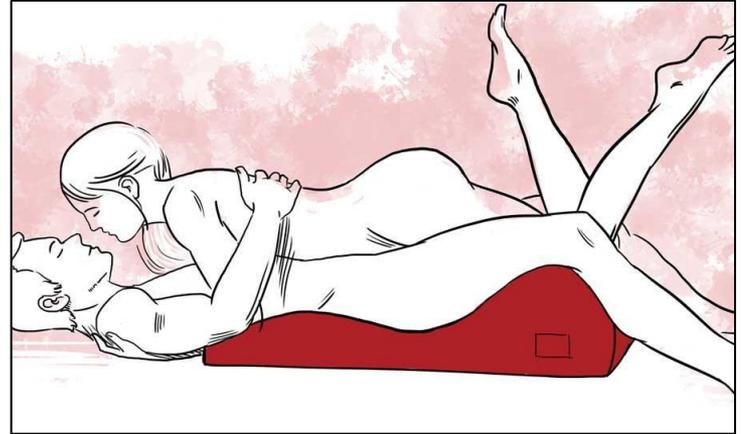
- **Pain**

- Positioning
- Massage, hot/cold – what helps reduce your pain? Do it prior or as part of foreplay

Helpful Strategies (Continued)

- **Bowel/bladder incontinence**
 - Bowel/bladder schedule – time sexual activity accordingly
 - Shower/bathtub
 - Positions with less pressure on the bladder
- **Caregiver setup** – Whether for solo exploration or with a partner, your caregiver could provide setup assistance to make sure you have everything you need within reach.
 - This just means you will have to have some conversations to make sure you both are comfortable and have clear expectations for the responsibility.

Pillows & Furniture



There are a variety of pillows or furniture pieces designed specifically for sexual intimacy. You can also try using typical pillows or bean bags to add support.

Pillows & Furniture



This adjustable product can alleviate pressure on joints during sexual intimacy, allowing for more comfort.

Lubricants



Lubricant can be help if you are experiencing vaginal dryness. There are different types of lubricants with pros/cons of each type.

The most common types are:

- Water-based
- Silicone-based

Desensitizers



There are sprays, gels, and lubricants designed to numb the penis and **delay premature ejaculation**.

These can also be **helpful if you experience hypersensitivity**, and there are versions for people with vaginas as well.

There are over-the-counter versions as well as versions your doctor could prescribe.

Vibrators & Dildos



These can be helpful for those who need extra stimulation, have difficulty reaching their own or their partner's genitals, become fatigued quickly, have difficulty maintaining an erection, etc.

And More!



As sex toys have become more mainstream, there are now so many options easily available online or in a well-stocked sexual health store.

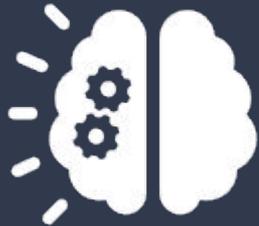
A reputable store (such as Good Vibes, two locations in Boston/Cambridge), would be happy to assist with problem-solving and choosing sex aids that will meet your needs.

Cognitive, Emotional, and Role Changes after ABI

*Overview, treatment and support options,
strategies to increase communication &
intimacy*



Cognitive Symptoms That May Impact Sexual Participation



- **Memory issues**
- **Reduced motivation/initiation**
- **Difficulty sustaining attention**
- **Lack of insight/self-awareness**
- **Declined decision-making and planning abilities**
- **Communication difficulties**
- **Disinhibition**

Helpful Strategies for Cognitive Symptoms

- **Memory and motivation** – Consider planning a “date night” ahead, mark it on a calendar or planner, give reminders, build a routine
- **Memory and planning ahead** – Consider contraception options that don’t require as much thought (an IUD vs. a daily birth control pill)
- **Attention issues** – Choose a quiet location with minimal distractions



Helpful Strategies (Continued)

- **Communication difficulties** – If speaking is difficult, consider using hand signals or one-word phrases during sex. Working out likes/dislikes explicitly before and during sex will be important to make sure both partners are comfortable.
- **Disinhibition** - If the person has said or done something inappropriate, kindly inform them. Remind them of where they can engage in sexual behavior privately.



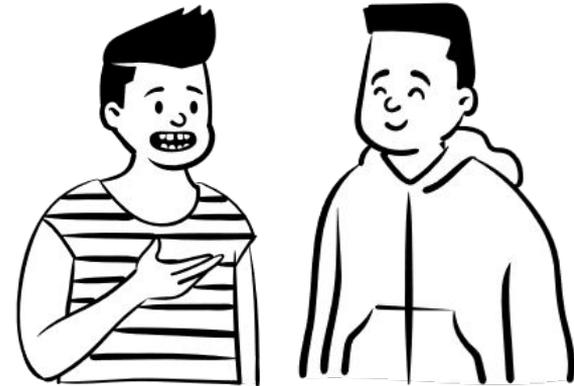
Socioemotional Changes That May Impact Sexual Participation



- **Depression**
 - One of the strongest predictors of poor sexual outcomes after TBI (*Fraser, et. al., 2020*)
- **Emotional lability**
- **Loss of self-esteem**
- **Decreased empathy**
- **Grieving loss of former sense of self**
- **Change in relationships and social activities**
- **Role changes**
 - Caregiver/receiver

Treatment/Support Options

- **Seeing a qualified therapist** can help both the person living with a brain injury and the partner to cope emotionally with the grief, loss, and change they are experiencing.
- **Couples therapy** can support improved communication in the relationship in general and specifically around sex.
- **Support groups** are a great way to connect with other people who “get it”
- Your **primary care provider (PCP) or psychiatrist** may be able to treat depression or anxiety that is impacting your sex life with medications.



Improving Communication

- **Communicate!** – in general, about your relationship, about your love for each other, about your fears and feelings and hopes and dreams... but also about sex
 - **Don't assume** your partner knows how you are feeling about sex or what you want. Open, honest conversation will foster connection and allow for problem-solving as needed.
 - Difficult conversation to initiate? **Set ground rules** for the conversation: listen, be kind, remember you love each other, work together, be willing to try new things
 - **Utilize couples therapy for assistance** navigating difficult conversations if needed

Improving Communication (Continued)

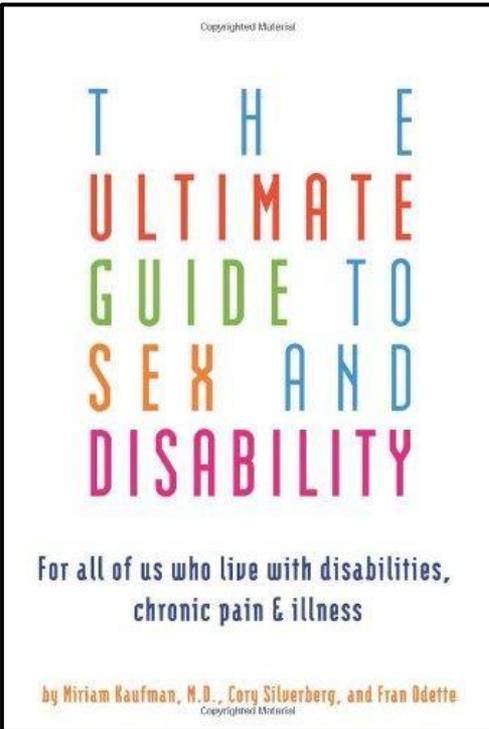


- If you are single/dating, it is your **personal choice when to disclose** your brain injury or any sexual challenges you may experience
 - Communication remains key, remember the **best relationships are built on a foundation of trust and clear communication**
 - **Remember your worth**, you can be an excellent romantic and sexual partner despite your brain injury – it just may mean making some adjustments and the right partner won't be deterred by this

Helpful Strategies

- **Start small** – Build moments of physical affection and appreciation into the day: hand-holding, kissing, flirty touches, other “foreplay”, acts of kindness, compliments, etc.
- **Set the mood** – Create a relaxing, romantic environment when possible to help ease nerves and foster desire
- **Take care of your mental health** – meditation, mindfulness, positive self-talk, gratitude journaling, exercise if you can, etc.

Some Selected Resources



- This book is an excellent resource for survivors, partners, and professionals alike. Includes lots of good information and resources.
- Headway - an UK-based organization for brain injury has some great booklets and fact sheets in their information library about sex and relationships: <https://www.headway.org.uk/about-brain-injury/individuals/information-library/>
- www.aasect.org has directory of sex therapists and counselors

Questions? Comments?

Thank you for listening! Please feel free to contact me:

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Interested in learning more about
Krempels Center, a specialized
therapeutic community for people
living with brain injuries? Check out:

www.krempelscenter.org

We are online and in Portsmouth!



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