

Disability and Barriers to Sexual Expression

Editor's Note: The content of this article is for informational purposes only and should not be taken as advice.

There are numerous myths and stereotypes about sexuality and individuals with brain or spinal cord injuries. A common belief is that people in wheelchairs are asexual and don't have sexual urges or thoughts. Contrary to this mistaken belief, people with disabilities have sexual thoughts, express sexual desire, and are capable of engaging in sexual activities.

Individuals with traumatic brain injuries (TBI) and/or spinal cord injuries (SCI) not only have to combat the myths about sexuality and disability but also the many barriers that are brought upon by their injuries. Whether someone is in a 24-hour supervised facility or living at home, people with TBI and SCI face numerous challenges with sexual expression.

Physical and physiological barriers

Physical impairments are one of the most common challenges of sexual expression for people with a brain or spinal cord injury. Some may have balance or walking issues or require the use of a wheelchair, while others might have limited use of their arms or hands. Whether it's fine motor coordination impairment, decreased sensation, or incontinence, there are ways around the impairments to enable people with disabilities to have fulfilling sexual experiences.

The following are a few examples of compensations for impairments that may limit sexual activity:

Fine motor coordination impairment

For those with fine motor coordination deficits, independent sexual expression or using assistive devices may be difficult. Fingers and hands may not have the dexterity needed to hold onto a device or reach intimate areas of the body. Thus, modifications to current devices or acquiring new ones that accommodate for poor fine motor control should be explored. For example:

- Adaptive switches and built up handles, which allow users a larger button to turn the device on or off and control speed.
- Remote control or partner-operated devices.
- Stationary or anchored equipment.



Ataxia, tremors, or spasticity

For individuals with these types of deficits, it would again be best for hands-free use such as anchored or stationary equipment. For example, equipment can be anchored to a shower chair for easy use in the shower.

If at all possible, the individual should do as much of their own set up as their physical and cognitive impairments allow. If help is needed with set up, a loved one or trained staff may be able to provide assistance. Set up should be done with dignity and should allow for privacy.

Decreased sensation

Individuals with brain injuries often have decreased sensation as a result of their injury. Devices are available that have strong vibration that can be used. If decreased sensation in one area of the body in particular is the problem, try other areas of the body. For instance, individuals with certain types of spinal cord injuries have a line on his or her body where the sensation stops. That line where sensation ends and begins is very sensitive and can be explored for sexual responses.

In addition, experimentation with different kinds of touches, firm massages, or gentler strokes can help individuals with newly acquired injuries to find out what parts of their body respond best to intimate stimulation.

Incontinence

Incontinence is a common side effect of having a brain or spinal cord injury. Impulses between the brain and the bladder/bowels may not be functioning, thus resulting in the inability to regulate or control these bodily functions. For individuals with incontinence issues, performing a bowel and bladder program before sexual activity can lead to more confidence with partners.

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Fatigue and low endurance

As the brain and body recovers from injuries, fatigue is a common occurrence. Engaging in sexual activities with partners requires a certain level of endurance. To counteract for the lack of endurance, the use of adaptive equipment can be useful. Focusing on non weight-bearing activities is also useful. Lying on one's side is gentler on the joints and less taxing.

Medications and effects on sexuality

Medications are often used as part of the recovery process for those with a brain or spinal cord injury. Medications can be used for a variety of reasons including treating pain, depression, seizures, attention deficits, and more. Some medications have sexual side effects that may cause erectile dysfunction and reduced sexual drive. These medications may be a crucial part of recovery, therefore, talking to a physician about any sexual side effects can lead to possible solutions to alleviate them. One should never stop taking medications without talking to a physician first.

Environmental barriers

The Residential Home Environment: If sexual expression is part of an individual's treatment program that has been set up by the client and/or guardian, privacy can be an issue in a residential home setting. Individuals with brain or spinal cord injuries may require varying levels of supervision and assistance and therefore present some inherent environmental barriers to sexual expression:

- 24-hour staff who are required to know where clients are and what they are doing.
- Roommates (common in nursing homes and some assisted-living facilities).
- Who sets up/cleans up – finding staff who are comfortable with assisting clients with set up and clean up may be difficult.
- Knocking as entering. Staff or visitors may knock as they are opening a client's bedroom door, which does not allow the person in the room enough time to respond. In non-emergency situations, staff should be respectful and make sure the client responds before entering his or her room.
- Policies of a facility: Therapists and staff should be aware of their company's policy on sexuality before engaging in therapeutic intervention for sexual expression.

Sensitivity training of direct care staff

The residential home is an environment where sexuality is not normalized. Rather, it can be viewed as taboo, dangerous, or risky and as such it is often perceived by staff, managers, or therapists, as inappropriate behavior. This leads people to think of sexuality in residential homes as problematic, reinforcing the notion that it is always a challenging and difficult topic on which to train direct care staff.

For optimal results, training of direct care staff on how to talk to individuals about sexuality, provide support, and communicate with other treatment team members on this topic is recommended. An untrained staff member can easily make the client feel guilty and ashamed for having sexual thoughts, or acting on these thoughts. Studies show that clients in assisted-living facilities without any outlets for sexual expression can become more aggressive and develop attention seeking, inappropriate sexual behaviors¹.

Cognitive barriers

Common cognitive deficits after TBI include memory loss, disinhibition, impulsivity, and poor decision making. All of these can become barriers to sexual expression.

Memory

Difficulty with memory is one of the most common cognitive deficits experienced following an injury to the brain. These difficulties usually affect the person's ability to function independently².

It can also affect the person's sexual functioning. An individual can forget new people they meet, therefore, missing opportunities for relationships. They can also forget to plan for safe sexual activity, thus leading to unsafe sex and possible STDs. Below are a list of tools to assist with memory loss:

- Effective use of a planner.
- Use alarm watches to remember birth control medication.
- Carry protection to compensate for spontaneity.
- Seek the advice of your treatment team for planning dates and special occasions.

Impulsivity, disinhibition and poor decision making

Damage to the frontal lobe can cause disinhibition with all types of behaviors, including sexual expression. This makes it difficult to engage in conversations with potential partners without making unwanted or inappropriate sexual comments or advances leading to social isolation.

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In the early stages of TBI recovery, some individuals experience decreased alertness, confusion and greatly reduced awareness. Behaviors, such as self-exposure and/or self-stimulation, may be present regardless of the environment. It is important to remember that awareness of and ability to control this behavior has been affected by the brain injury.

In later stages of TBI recovery, additional issues pertaining to sexuality may be observed. Although the person's level of alertness and responsiveness is generally increased, cognitive difficulties such as impairments in memory, orientation, insight, and judgment, continue to be common.

Responsiveness is sometimes characterized by impulsiveness (acting before thinking through the consequences of behaviors), including the person's sexual responsiveness. As a result, normal sexual thoughts and feelings are not censored or inhibited as they are with a non-injured person. This extends to remarks and actions that reflect sexual thoughts and are inappropriate to the immediate circumstances, such as touching and repeated sexual references³.

Sexuality is a vital factor that contributes to the sense of identity each of us develops as a social and emotional being. Expression of sexuality is significantly influenced by self-esteem and self-perception, or, by the way we see ourselves in relation to our environment and other people around us.

Changes in appearance, thinking skills, and/or physical changes related to brain injury and spinal cord injury alter an individual's self-perception and result in accompanying changes in the expression of sexual thoughts and impulses. He/she is often insecure about the ability to express and experience affection and concerned about attractiveness and sexual effectiveness.

Sexuality is a valid rehabilitation issue for the individual with TBI that requires support and understanding from the family and treatment team. Open discussions about sexuality and sexual expression are important between clients and the treatment team. Direct care staff, residential home managers and therapists should be trained and feel comfortable discussing sexuality with clients and provide the needed support to achieve their optimal sexual functioning. ❖

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