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Drs. Miljkovic and Tita report no relationships with proprietary entities producing health care goods and services.

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# Let's Talk About Sex (After Stroke)

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## Clinical Vignette

RS is a 72-year-old, right hand dominant, male retired psychologist with a history of hypertension and coronary artery disease who suffered a left middle cerebral artery distribution ischemic stroke. He is currently completing a course of comprehensive inpatient rehabilitation and is preparing for discharge home with his wife. His most significant impairments include right spastic hemiparesis, moderate expressive aphasia, and urinary incontinence. Functionally, he is able to ambulate short distances with moderate assistance and requires minimum to moderate assistance with most activities of daily living. The rehabilitation plan for RS at discharge is to continue home-based therapy and then transition to outpatient therapy.

The patient's wife, 14 years his junior, is concerned about him going home and has many questions for his rehabilitation team. One of the questions that makes her particularly uncomfortable is whether she and her husband will ever be able to have an intimate sexual relationship again. Prior to the stroke, this was an important part of their marriage, and she worries that this part of their lives may be gone forever. She asks if there is any hope for them, and if so, are sexual relations safe after a stroke?

## Define the Problem/Epidemiology

Sexual dysfunction is defined as "the difficulty experienced by an individual or couple during any stage of a normal sexual activity, including physical pleasure, desire, preference, arousal, or orgasm."<sup>1</sup> While the precise incidence of sexual dysfunction following stroke is not known, stroke survivors consistently report decreased sexual activity and increased sexual dysfunction,<sup>2-7</sup> and an estimated 20 to 75 percent of stroke survivors have some degree of sexual dysfunction.<sup>7-14</sup> This rate is significantly increased compared to general population estimates of 40 to 45 percent of adult women and 20 to 30 percent of adult men, and a greater degree of dependence in activities of daily living appears to be the most significant predictive factor.<sup>11,15</sup> In spite of the high prevalence of sexual dysfunction following stroke, many rehabilitation programs do not include a consistent approach to addressing post-stroke sexuality.<sup>14</sup>

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In an anonymous survey of patients from a stroke registry at Columbia University on their counseling preferences, 71 percent of respondents identified sexuality as a moderately to very important issue in their post-stroke rehabilitation. Additionally, 81 percent of respondents reported receiving insufficient information about sexuality post-stroke, and 60 percent expressed preference for receiving that information from a physician.<sup>14</sup> These results are consistent with multiple similar studies and questionnaires performed over the past several decades.<sup>16-19</sup>

There are multiple reasons why sexuality after stroke is rarely approached during the inpatient rehabilitation process. Rehabilitation physicians generally lack training on how to approach this topic, feel embarrassed to do so, or fear causing offense to the patient.<sup>14</sup> Patients and their partners often believe that sex after stroke is not safe, should not be a priority in their recovery, or simply don't know who to talk to about this topic.<sup>14</sup> In order to overcome these barriers on both sides, physiatrists should become proactive and always include discussions about sex/intimacy after stroke, even if not asked about it.

## Physiology of Sexual Function

Sex is a complex multidimensional phenomenon that incorporates biological, psychological, interpersonal, and behavioral dimensions. From a biological standpoint, both central and peripheral neural pathways play key roles in proper sexual function, in addition to the interplay between the sympathetic and parasympathetic nervous systems.<sup>5,8,20</sup> All models of the human sexual response acknowledge the importance of sexual drive or desire, physical arousal, and physical or emotional satisfaction in enabling the process to occur successfully.<sup>20,21</sup> (See Figure 1.)

Sexual drive or desire is what leads a person to pursue sex. The areas of the brain selectively involved in this process include the frontotemporal and parietal lobes, as well as the anterior cingulate cortex. These brain areas are either stimulated or inhibited by both psychological and biological factors.

Stimulating factors include pleasurable sensations or memories of pleasurable experiences, while inhibitory factors include feelings of insecurity, memories of past negative experiences, general distractedness, or fatigue.<sup>8,20,21</sup>

Arousal refers to the physiologic excitement that precedes and enables sexual intercourse. This process relies on the amygdala, hypothalamus, and septal regions of the brain for regulation of the neuroendocrine axis and autonomic nervous system.

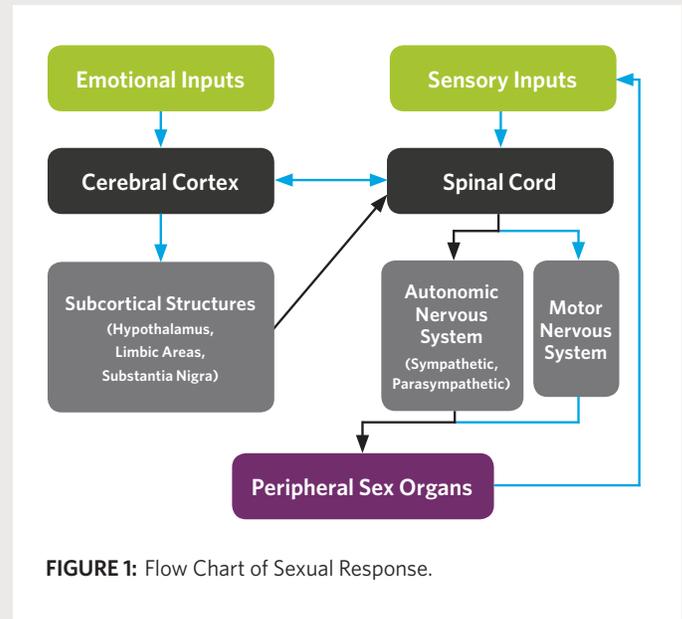


FIGURE 1: Flow Chart of Sexual Response.

With the help of brainstem and spinal reflexes, this phase leads to generally increased muscle tone and vasodilation of the genitals.<sup>8,20</sup> Depression is a very common biological factor that inhibits sexual arousal, likely owing to reduced levels of norepinephrine and adrenaline in the locus coeruleus and raphe nuclei resulting in decreased ability to appreciate and respond to sexual stimuli.<sup>22</sup>

Physical or emotional satisfaction is what generally constitutes the conclusion of an intimate sexual encounter, though the process does not always occur in a linear fashion. This phase may or may not include orgasm, which is the result of the reflexive release of increased muscle tone and vasodilation brought on by sexual arousal.<sup>8,20,21</sup>

## Sexual Dysfunction Following Stroke

Since stroke causes injury to brain tissue, the aspects of sexual response that tend to be most affected following stroke are those that occur within the brain itself, such as: 1) decline in libido and coital frequency in both sexes; 2) erectile or ejaculatory dysfunction in males, and 3) loss of vaginal lubrication and orgasm in females.<sup>7-12</sup> Very rarely, deviant sexual behavior or hypersexuality may result after stroke.<sup>10,23</sup>

Other than brain injury itself, the etiology of sexual dysfunction after stroke is multifactorial and relates to psychosocial factors, physiologic changes, medical and medication issues, and even age-related issues.<sup>8,15,16</sup>

## Psychosocial Factors

Psychosocial factors appear to be the dominant cause of sexual dysfunction in the post-stroke population.<sup>8,11,12,15</sup> These factors include altered body image, decreased self-esteem, loss of desire for or pleasure from sexual activity, dependency in performing activities of daily living (ADLs), role shifting within the family or relationship, and impairment in social dimensions.<sup>8,14-16,24-25</sup>

- 1) **Poor body image and low self-esteem.** Residual impairments such as facial drooping, hemiparesis or hemiplegia, dysarthria, drooling, aphasia, and incontinence can cause patients to feel less attractive and subsequently lead to avoidance of sexual situations.<sup>14-15</sup> It is important to encourage participation in both sexual and nonsexual activities that increase feelings of wellness and pleasure.<sup>25</sup> Additionally, encouraging small investments in personal appearance, such as changing out of pajamas/robes, shaving, applying makeup, or styling one's hair, can be very helpful in improving self-esteem and overall outlook.
- 2) **Role shifting.** When a stroke survivor requires assistance for ADLs, the partner sometimes experiences difficulty shifting roles from caregiver to lover.<sup>26</sup> The stroke also may result in changes to the overall dynamics of a household with partners changing roles as financial provider or home manager. Such shifts can sometimes result in anger, frustration, and resentment from both partners, and many couples find it difficult to adjust to the new routine.<sup>13,24-25</sup> In these instances, it is important to emphasize that adjustment to any new circumstance takes time and patience. Another suggestion is to have someone other than the partner carry out certain aspects of care, such as toileting or bathing, to allow for some separation between partner and caregiver roles.<sup>26</sup>
- 3) **Impairment in social dimensions.** Stroke survivors who are single have significant fear and anxiety over dating and seeking romantic relationships, which can lead to depression and social isolation.<sup>14-15,24</sup> To further complicate the issue, romantic and sexual needs of single persons following stroke very frequently go unaddressed by clinicians because the need to discuss these issues is less readily apparent when there is no identified partner. In fact, no clear correlation has been shown between the incidence of sexual dysfunction and marital status,<sup>10</sup> marriage/partnership duration, or educational level,<sup>12</sup> so it is important to address the topic with all patients. Physicians also can encourage self-exploration of sexuality in the post-stroke setting, respecting the fact that this is a normal part of overall well-being.<sup>20</sup>

## Physiologic Factors

Physiologic factors are a significant barrier to resuming sexual activity following stroke, as many patients and their partners struggle to understand the logistics of how it can be done safely. Some specific barriers include:

- 1) **Weakness** (hemiparesis or hemiplegia) can have a profound impact on a couple's ability to engage in many sexual activities due to difficulty with positioning.<sup>24</sup> Enlisting the assistance of an experienced occupational therapist may be of benefit in allowing a couple to explore alternate positions that enable sexual intercourse. Sometimes reframing intimacy or encouraging experimentation with alternate forms of stimulation outside of intercourse may be appropriate.<sup>26,27</sup>
- 2) **Spasticity** can also be an issue for stroke survivors, and the timing of antispasticity medications may be either beneficial or detrimental to sexual activity. Hip adductor tone in particular can pose a significant barrier to sexual activity for both men and women, so assessment of these muscles must be included in any comprehensive spasticity evaluation. It is helpful to encourage patients to stretch or exercise prior to engaging in sexual activity to decrease the impact of spastic muscles, and in certain cases interventions such as chemodenervation may be helpful.<sup>15,26</sup>
- 3) **Sensory changes**, such as paresthesia, allodynia, and insensate skin require position awareness and activity adjustment following stroke. Insensate skin is at risk for breakdown, and shearing forces or friction can result in wound formation so it is important to check skin thoroughly before and after any sexual activity. Alternatively, sensation changes may sometimes result in the emergence of new erogenous zones, which can be pleasurable to explore.<sup>26</sup> If post-stroke pain is a substantial barrier, it may be useful to time pain medications or sexual activity to coordinate with times when pain is best controlled.<sup>27</sup>
- 4) **Fatigue** in both patients and their caregivers negatively impacts sexuality after stroke.<sup>28-30</sup> It is important for physicians to encourage flexibility in timing of sexual activity, as well as optimize patient sleep cycles, paying particular attention to the timing or use of sedating medications. Alternatively, physical training to improve stamina may facilitate tolerance of sexual intercourse and may even increase sexual desire.<sup>20,27</sup>

- 5) **Urinary incontinence** secondary to neurogenic bladder is relatively common following stroke and may result in avoidance of sexual activity due to fear of embarrassment or inconvenience.<sup>12,26</sup> This issue should always be explored and treated as appropriate, but in addition, couples should be informed of strategies that can be employed to minimize the risk of urinary leakage during sexual activity. These may include timed voiding prior to sex, temporary fluid restriction several hours prior, and avoiding positions that put excessive pressure on the bladder. If a catheter is used, it can be either temporarily removed or covered with a condom in males, or taped to the side in females.

### Medical Factors (Comorbidities and Medications)

The majority of stroke patients have multiple medical comorbidities that either contributed to causing or emerged as a result of their stroke. The most common among these are hypertension, heart disease, diabetes mellitus, seizures, and depression. Unfortunately, both the pathophysiology of these conditions as well as their treatment can serve as potential barriers to normal sexual function after stroke.<sup>25</sup>

In the case of **diabetes**, vasculopathic and neuropathic changes resulting from persistently elevated blood glucose can result in various forms of sexual dysfunction. In both men and women with diabetes, decreased libido is often seen. In addition, men with diabetes also often have erectile dysfunction (ED), and women with diabetes tend to have reduced vaginal lubrication and increased incidence of vaginal infections.<sup>25</sup> Tight control of blood glucose may help to minimize these issues.<sup>20</sup>

**Erectile dysfunction (ED)** is one of the most common forms of sexual dysfunction in men following stroke.<sup>9</sup> The mechanism of ED appears to be endothelial dysfunction impeding proper arteriole dilatation in response to stimuli.<sup>8,31</sup> This diagnosis predates the patient's stroke, but concomitant psychosocial issues following the stroke can exacerbate it. Risk factor modification is an appropriate first line of treatment of ED, including weight loss, smoking cessation, and exercise. These strategies have the potential to enhance sexual function at any age.<sup>27</sup>

For many rehabilitation physicians, treatment of ED is a point of hesitation due to fear of causing unsafe drops in blood pressure that could result in ischemia. This concern has been explored

extensively among patients with cardiovascular disease. The American Heart Association and American College of Cardiology expert consensus is that type 5 selective phosphodiesterase inhibitors (PDE5 inhibitors) do not pose any additional risk of ischemia and are safe for patients with stable heart disease who are not taking nitrate medications.<sup>31</sup> Indeed, these medications are the standard of care for treating ED regardless of the cause, and they are used widely in the post-stroke population. The authors recommend coordination of care with the patient's primary care physician and/or cardiologist when considering initiation of PDE5 inhibitors.

For **hypertension and heart disease**, treatment side effects may be just as significant a contributor to sexual dysfunction as the diseases themselves. Beta-blockers and diuretics tend to have the most negative impact on sexual performance, while ACE-inhibitors and ARBs tend to have minimal sexual side effects.<sup>32</sup> There is even some evidence to suggest ACE-inhibitors and ARBs may be helpful in treating mild to moderate ED since these medications block angiotensin II (Ang II) which results in down-regulation of the angiotensin type 1 receptor in the corpora cavernosa, as well as locally generated Ang II, halting the positive feedback loop.<sup>33</sup> While cardiovascular medications that improve patient's symptoms and survival should not be withheld out of concern for adverse sexual side effects, physicians should consider dosage adjustments or switching to an alternative drug or class of medication if the change could improve sexual functioning.<sup>27</sup> (See *Figure 2 on Page 5*).

It is also important to help patients and their partners recognize when they are healthy enough to attempt sexual activity, as many post-stroke couples report fear of sex causing a recurrent stroke.<sup>8-9,12,24-25</sup> In fact, typical energy expenditure during sex is approximately 3 to 5 metabolic equivalents (METs), which is roughly equivalent to climbing two flights of stairs or walking on a treadmill at a pace of 3-4mph. Once a patient is able to tolerate exercise at 3 to 5 METs without symptoms, it is reasonable to assume that sexual activity is safe.<sup>26</sup> For patients who are unable to tolerate this degree of energy expenditure, encouraging noncoital activities that require less energy expenditure, such as hugging, kissing, or touching, can promote intimacy without potentially compromising cardiac function.<sup>26</sup>

**Depression** is the most common psychiatric occurrence following stroke, affecting more than a third of stroke survivors,<sup>34,35</sup> and is a very common cause of sexual dysfunction both in survivors and their caregivers.<sup>5,8,10,12,14-15,21,25</sup>

Class	Erectile Dysfunction	Decreased Libido	Impaired Ejaculation	Priapism	Gynecomastia
Beta-blockers	+	-	-	-	+
Spironolactone	+	+	-	-	+
Thiazides	+	+	+	-	-
CCBs	-	-	+	-	+
ACE-inhibitors	-	-	-	-	-
ARBs	-	-	-	-	-
Vasodilators	+	-	-	+	-
Central antiadrenergics	+	+	+	-	-
Peripheral antiadrenergics	+	-	+	+	+

**FIGURE 2:** Potential sexual side effects of commonly prescribed antihypertensive/heart disease medications. (Table adapted from Nicolai MJ, et al. *Netherlands Heart J.* 2014)

While treatment of depression or anxiety can help resolve issues with sexual dysfunction, many of the common medications used to treat these conditions, such as SSRIs and SNRIs, also may contribute to sexual dysfunction. While the mechanism by which antidepressants cause sexual dysfunction is not fully understood, stimulation of the 5-HT<sub>2C</sub> receptors appears to be implicated. When there is concern that a patient's sexual dysfunction may be related to medications, changes should be considered that include using a reduced dose or scheduling the dose after sexual activity.<sup>15</sup> Bupropion, mirtazapine, and nefazodone appear to be much less often associated with sexual dysfunction, likely due to less direct effect at the 5-HT<sub>2C</sub> receptors, and may be good alternative treatment options in this population.

**Seizure disorders** occur in up to 10 percent of stroke patients and are correlated with increased incidence of sexual dysfunction, usually hyposexuality. Chronic use of antiepileptic drugs (AEDs) contributes to this dysfunction due to alternations in the neuro-endocrine axis.<sup>36</sup> Similar to depression, sexual dysfunction secondary to AEDs can be potentially treated by decreasing the AED dose or switching to an alternative drug. These changes may not completely resolve the issue since epilepsy itself appears to be associated with sexual dysfunction independent of treatment.<sup>36</sup>

#### Other Factors (age, cognition, and aphasia)

- Age-related changes.** For both elderly men and women, it often takes longer and more direct stimulation to achieve sexual arousal and reach orgasm as they age. Society tends to view elderly adults as asexual, so sexual dysfunction is rarely identified or addressed in this population. Instead, medical professionals should use a proactive approach to evaluating sexual function with people of all ages, asking about it routinely and encouraging open communication on the topic.<sup>27</sup>
- Cognitive impairment.** Patients with memory problems may lose track of what they are doing or have trouble maintaining attention during sexual activity. Partners should be advised to minimize potential distractions and use a combination of familiar verbal and nonverbal cues to maintain focus. Certain stimulant medications may be helpful to maintain attention during the encounter. For people who develop sexual perseverations as a part of their cognitive impairment, creation of a written log of sexual activity may be helpful.
- Aphasia.** For patients who have difficulty expressing themselves verbally, professionals should encourage them to let nonverbal communication guide activity. Couples should also establish a means of communicating key phrases such as "I love you."<sup>26</sup>

## Treatment Strategies

The first question to address is: When is the most appropriate time to talk about sexuality following stroke? In general, this topic should be introduced during the course of inpatient rehabilitation, preferably during preparations to return home, and then again at regular intervals in outpatient follow-up visits.<sup>16,27</sup>

A **comprehensive medical evaluation** should always precede any treatment or intervention for sexual dysfunction.<sup>27</sup>

Such an evaluation should include:

1. Review of sexual, medical, and psychosocial history
2. Comprehensive physical exam
3. Laboratory testing when appropriate
4. Review of medications
5. Review of lifestyle factors (smoking, alcohol use, diet)
6. Distinguish disease pathology from normal aging<sup>15</sup>

The next step would be to engage in some form of **sexuality counseling**, which includes providing education, insight, available resources, and reassurance that their experience and concerns are normal. The goal of sexuality counseling is to dispel stereotypes, myths, and misconceptions, as well as promote a perception that sexual expression is a natural part of life that should be enjoyed, even after stroke. Specific patient or partner concerns should be addressed as they arise, and even when problems cannot be resolved completely, discussion of sexual issues can help with patient and partner understanding.<sup>27,31</sup>

The timing of when to resume sexual activity after stroke is personal and will vary with each patient. Factors such as medical stability, availability of a partner, and privacy may all influence this decision. Patients often know when they are ready, and they may tell you so. Rehabilitation professionals should encourage couples to first focus on rebuilding nonsexual intimacy, such as hugging, touching, and cuddling. The couple can progress to intercourse as comfort levels adjust and understanding of how to do so safely improves.

At times, it may be appropriate to provide referral to a specialist for further treatment, such as a urologist, gynecologist, occupational therapist, psychologist, or certified sex counselor. For a list of potential patient and professional resources on sexual dysfunction and assistance after stroke, see “Resources for Further Information.”

## Resources for Further Information

- American Association of Sexuality Educators, Counselors and Therapists - [www.aasect.org](http://www.aasect.org)
- PleasureABLE Sexual Device Manual for Persons With Disabilities by Naphtali, MacHattie, Krassioukov, and Elliott - [http://www.dhrn.ca/files/sexualhealthmanual\\_lowres\\_2010\\_0208.pdf](http://www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf)
- Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People who Care About Them) by Kroll and Klein
- The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness by Kaufman, Silverberg, and Odette
- Hope for Love: Practical Advice for Intimacy and Sex After Stroke by Kautz
- When Your Spouse Has a Stroke by Palmer and Palmer
- The Stroke Recovery Book: A Guide for Patients and Families by Burkman

## Clinical Vignette Outcome

After being approached by the spouse with the question of intimacy after stroke, we addressed her concerns as a team. The attending physician had an individual conversation with her on what to pay attention to concerning the medical issues associated with her husband’s stroke, such as blood pressure, spasticity, bladder function, etc. She met with the neuropsychologist who helped her better understand the emotional part of intimacy after stroke and how to work on becoming close again. Lastly, the spouse talked to our case manager — who is a trained spinal cord injury (SCI) nurse — who helped answer the practical questions the spouse had about appropriate positioning for sex. A few weeks later, the spouse called our case manager and was very happy to share the news that she and her husband were able to experience intimacy again despite his stroke impairments.

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