

Sex and Intimacy After Stroke

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Introduction

- ▶ Who I am
- ▶ What I'm going to talk about
- ▶ Participation
 - ▶ Talking
 - ▶ Not talking
 - ▶ Values and respect for differences

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Objectives/Overview

- ▶ Definitions
- ▶ Aspects of stroke that affect sex and sexuality
- ▶ Things you can do to improve your sex life with your partner
- ▶ Starting new romantic relationships after stroke
- ▶ How healthcare providers can help

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Putting Sexuality in Context

- ▶ Sex and sexuality as an "activity of daily living" (ADL) (i.e., regular activity of adult life).
- ▶ In same category as eating, dressing, bathing, grooming, toileting, speaking.
- ▶ Sex and sexuality are integral parts of adult life. This includes expressing your sexuality, having intimate sexual relationships, and being able to participate in sex acts (alone and with partners).

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Definitions

- ▶ **Sex/sex drive**
 - ▶ Basic human drive (like hunger, thirst).
 - ▶ “Libido.”
 - ▶ Allows us to reproduce, experience unique pleasure, reduce tension, and create intimacy with a partner.
 - ▶ We all have it—regardless of whether we express it.
 - ▶ Stroke does not take away your sex drive. It can be lessened or increased after a stroke, but not eliminated.

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Definitions

- ▶ **Sex acts**
 - ▶ Behavioral expression of your sex drive.
 - ▶ May be expressed alone or with/to another person.
 - ▶ Involves sexual contact; sexual stimulation.
 - ▶ Kissing, touching/fondling, oral sex, intercourse, masturbation, etc.
 - ▶ ONE aspect of sexuality. Typically not directly affected, or minimally affected, by a stroke.

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Definitions

- ▶ **Sexual function**
 - ▶ The ability to engage in particular types of sex acts.
 - ▶ Achieve erection; orgasm; lubrication (dryness).
 - ▶ Has both physical and psychosocial elements.
 - ▶ Can be affected by stroke and its consequences.
 - ▶ Hemisensory syndrome; medication side effects; depression.

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Definitions

- ▶ **Sexuality**
 - ▶ Multidimensional and part of being human—here too, we all have sexuality.
 - ▶ We have sexuality whether or not we engage in sex acts. It's part of our identity as adults.
 - ▶ Sex acts are part of our sexuality, but not a requirement for the expression of sexuality.
 - ▶ The way in which people express themselves *may or may not be* affected by stroke (self-perception; engagement).

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Definitions

- ▶ **Sexuality**
 - ▶ Sexual feelings
 - ▶ Sexual fantasies
 - ▶ Sexual values and morals (when, where, and with whom we have sex; what kinds of sex acts are ok)
 - ▶ Body image, feelings of attractiveness; self-image (how we see ourselves)
 - ▶ Gender identity (identifying as male or female)
 - ▶ Feelings of masculinity and femininity
 - ▶ Sexual orientation (homo-, bi-, or hetero-sexual)
 - ▶ Self-expression/personal style
 - ▶ Dressing to enhance or play down our sexual side; flirting; use of voice and gestures or mannerisms;
 - ▶ Can be expressed independent of sex acts

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Definitions

- ▶ **Intimacy**
- ▶ **Physical**
 - ▶ Physical contact.
 - ▶ Touching, holding hands, embracing, being close.
- ▶ **Emotional**
 - ▶ Communication.
 - ▶ Sharing beliefs, likes, dislikes, aspects of your “inner world.”
 - ▶ Expressing yourself.
- ▶ Creates feelings of closeness when attended to on a consistent and frequent basis.
- ▶ Allows for caring and affection.
- ▶ Sexual expression and sex acts in a relationship are part of intimacy (both physical and emotional) and both types of intimacy affect sexual relationships.

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Sex and Sexuality After Stroke

- ▶ When you ask people who've had a stroke what they want....
 - ▶ They are still interested in sex!
 - ▶ They want to know more information about sex after stroke.
 - ▶ They want to continue to express themselves in terms of their sexuality, and still feel sexual.
 - ▶ They want to engage in sex acts—regardless of relationship status (single, partnered).
 - ▶ Couples want to return to/continue their intimate sexual relationship.

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The Influence of Stroke on Sex

- ▶ If the interest and drive is still there, what's the problem?
 - ▶ Stroke has few direct effects on sex acts (sexual performance).
 - ▶ However, indirect effects may be present and these can affect performance and enjoyment of sex.
 - ▶ Most survivors do not get adequate information or counseling about sex from healthcare providers.
 - ▶ Communication gaps on both sides.

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Physical Changes that Affect Sex

- ▶ Physical changes after stroke can have an indirect effect on sexual function and sex acts:
 - ▶ Mobility impairments
 - ▶ Paralysis or weakness
 - ▶ Numbness and decreased sensation
 - ▶ Spasticity and pain
 - ▶ Medication side effects
 - ▶ Fatigue
 - ▶ Other medical conditions (diabetes, vascular disease, heart disease)

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Physical Changes that Affect Sex

- ▶ Medical problems and medications can interfere with the ability to have an erection.
- ▶ They can also cause fatigue or drowsiness.
- ▶ Impair sensation.
- ▶ Limit physical endurance.

- ▶ These are problems than can exist before a stroke (due to other medical problems), and then continue afterwards.
- ▶ It is essential to discuss these issues with your physician.

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Emotional Changes that Affect Sex

- ▶ Emotional (psychosocial) changes after stroke can also affect your sex life/relationships:
 - ▶ Fear of causing another stroke/pain/injury.
 - ▶ Medical research does not generally support this but if you have frank concerns, address them with your doctor.
 - ▶ Reduced self-esteem (feeling useless, unappreciated, etc.)—impairs our ability to feel sexy.
 - ▶ Reduced/negative body image—you may view your body differently and/or negatively, which can cause you to avoid sex or to view it negatively.
 - ▶ Fear of rejection.

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Emotional Changes that Affect Sex

- ▶ **Depression**
 - ▶ Effects all aspects of sex—interest, performance, and pleasure.
 - ▶ Is a common issue for stroke survivors and caregivers.
- ▶ Role changes and conflicts (sex partner & caregiver/care recipient)
- ▶ Worry or discomfort over talking about sex with your partner.
 - ▶ Tackling this soon and discussing it more often will make things easier.
- ▶ Uneasiness, discomfort, or worry about trying different sex acts
 - ▶ Trying new things; changing your routine.
 - ▶ Trying pleasurable acts that do not involve intercourse.
 - ▶ Masturbation.

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Cognitive Changes that Affect Sex

- ▶ The way we think and communicate affects how we express ourselves.
- ▶ A survivor's thinking and communication can also affect partner interest and pleasure.
- ▶ Cognitive problems caused by stroke:
 - ▶ Verbal communication/speaking/aphasia
 - ▶ Memory problems
 - ▶ Apathy
 - ▶ Difficulty with initiation
 - ▶ Disinhibition or inappropriate behaviors
 - ▶ Dementia/Child-like behaviors
- ▶ Counseling to sort out feelings related to these changes may be helpful.

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Yeah—We Know! What Can We Do About It?!

- ▶ **Make sex a priority**
 - ▶ DON'T put it on the back burner while you manage other aspects of your recovery and rehabilitation.
 - ▶ DO start talking about sex with your partner early on.
 - ▶ DO communicate your interest and desires as clearly and assertively as you can.
 - ▶ DO express physical affection as soon as you can. Soft touches, hugs, and light kisses can be a great place to start.
 - ▶ DO try new or different sex acts—including toys, masturbation, position changes.
 - ▶ DO schedule and “practice” sex—things won't be perfect to start, but keep experimenting and managing your expectations.
 - ▶ DO focus on giving and receiving pleasure rather than

▶ 18 “doing it right.”

Yeah—We Know! What Can We Do About It?!

- ▶ **Invest in your relationship and keep it alive.**
 - ▶ Be friends with your partner.
 - ▶ Have fun together.
 - ▶ Nurture your romance.
 - ▶ Balance time spent with your partner vs. time spent apart (along or with others).
 - ▶ Create boundaries between caregiving/receiving and being romantic or intimate with your partner.

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Yeah—We Know! What Can We Do About It?!

- ▶ **Manage your medical, physical, and cognitive changes as much as possible.**
 - ▶ DO take steps to maintain a healthy lifestyle with respect to nutrition, physical activity, and sleep.
 - ▶ DON'T reflexively rely on your caregiver for things that you can do independently (or semi-independently).
 - ▶ DO continue your rehabilitation exercises as prescribed by your providers.
 - ▶ DO continue to get treatment medical problems—especially depression.
 - ▶ DON'T stop getting help from professionals. After discharge from therapies, schedule periodic check-ups as needed to work on maintaining your gains. Plan for these appointments by writing down your questions and make a list of your concerns ahead of time.

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Yeah—We Know! What Can We Do About It?!

- ▶ **Manage your medical, physical, and cognitive changes as much as possible.**
 - ▶ DO schedule sex for times when you are less fatigued, rather than rely on it happening at the end of the day.
 - ▶ DO try different positions to minimize pain and discomfort.
 - ▶ DO make sure your partner can reach your “good side.”
- ▶ **Unique considerations for aphasia**
 - ▶ Share non-verbal activities to increase intimacy.
 - ▶ Don’t “force” verbal communication.
 - ▶ Use non-verbal communication to set the mood and communicate during sex: gestures, facial expressions, pictures, music, touch, demonstrations, vocalizations/pleasure sounds.

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Yeah—We Know! What Can We Do About It?!

- ▶ **Tips for Dating (and Friendships)**
 - ▶ DO get socially active—especially if you are looking for a partner.
 - ▶ Make a good first impression (hygiene, dress, attitude).
 - ▶ Meet people through your usual social networks as much as possible (maximize common interests).
 - ▶ Consider using online dating services. Make sure you meet your new dates in a safe, public place.
 - ▶ Think about expressing your sexuality when you meet a new person (rather than focusing on “having sex”).
 - ▶ Don’t talk in detail about your stroke on the first date. If you have to discuss it, keep it simple.
 - ▶ Keep specific sexual problems or concerns to yourself until you are sure you want to become sexually intimate with your new partner.

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Yeah—We Know! What Can We Do About It?!

- ▶ **If You Are Alone: Remember....**
 - ▶ Not everyone has or wants a sexual relationship.
 - ▶ Masturbation is a normal and healthy sex act for all adults, partnered or not.
 - ▶ Expressing your sexuality is pleasurable and healthy, whether you are partnered or not.
 - ▶ Stay connected to your friends, family, and neighbors. Social support is essential to recovery.

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When in Doubt—Call The Professionals

- ▶ **DO use professional help when needed.**
- ▶ **Things that usually get in the way of talking to a professional**
 - ▶ Embarrassment or shyness.
 - ▶ Assuming nothing can be done about your problem.
 - ▶ Health care provider’s discomfort or lack of knowledge.
- ▶ **How to overcome challenges**
 - ▶ Bring a list of questions.
 - ▶ Recognize there are numerous treatments for medical and psychosocial aspects.
 - ▶ Ask for a referral, if the provider you are talking to is not able to help.

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When in Doubt—Call The Professionals

- ▶ **Physical and Occupational Therapy (PT/OT)**
 - ▶ Energy conservation.
 - ▶ Positioning.
 - ▶ Strengthening.
 - ▶ Assistive devices.
 - ▶ Dressing and grooming to enhance attractiveness.

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When in Doubt—Call The Professionals

- ▶ **Speech/Language Pathologists (Speech Therapists/SLP)**
 - ▶ Improving language/speaking.
 - ▶ Improving communication (verbal and non-verbal).
 - ▶ Managing cognitive problems (memory).
 - ▶ Helping your partner understand—your difficulties and how to communicate.

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When in Doubt—Call The Professionals

- ▶ **Nurses and Physicians**
 - ▶ Treating erectile dysfunction (ED).
 - ▶ Treating pain.
 - ▶ Addressing fertility and pregnancy concerns.
 - ▶ Addressing catheter placement during sex.
 - ▶ Minimizing medication side effects (or trying new medications).
 - ▶ Addressing safe sex and birth control options.

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When in Doubt—Call The Professionals

- ▶ **Counselors, social workers, and psychologists (psychotherapists)**
 - ▶ Dealing with negative attitudes towards stroke and disability (yours, your partner's, or your potential partner's).
 - ▶ Finding social and leisure activities where you can meet potential partners.
 - ▶ Locating accessible dating venues.
 - ▶ Helping put your best foot forward to connect with potential partners.
 - ▶ Improving body image and self-perception.
 - ▶ Improving relationship problems.
 - ▶ Providing individualized sex therapy.

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In Conclusion

- ▶ It's natural to be interested in sex after your stroke. Most people are.
- ▶ Sexual problems after stroke can happen for a variety of reasons.
 - ▶ Physical, emotional, and cognitive/communication changes.
- ▶ There are many things you can do to improve and reclaim your sex life. You are most likely to do this if you enjoyed a good pre-stroke sex life.
- ▶ If you don't have a partner, you can express your sexuality and enjoy masturbation.
- ▶ It's possible to meet and date people after stroke.
- ▶ Professional help is available if you need it.

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For More Information

- ▶ National Stroke Association. Recovery After Stroke: Redefining Sexuality. Fact Sheet, available free at www.stroke.org/factsheets.
- ▶ StrokEngine. Sexuality Information for Patients and Families. www.strokingengine.ca
- ▶ American Heart Association. Sex After Stroke: Our Guide to Intimacy After Stroke. Order online at www.krames.com/aha.
- ▶ Sexual Health Network at www.sexualhealth.com.
- ▶ American Association of Sexuality Educators, Counselors and Therapists at www.aasect.org.
- ▶ Credit to: Dr. Sara Palmer, Assistant Professor, Johns Hopkins University

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Resources for Getting Help

- ▶ UWMC Rehabilitation Medicine/Rehabilitation Psychology (staff include PT, OT, SLP, clinical psychology)
 - ▶ <http://www.uwmedicine.org/locations/rehabilitation-medicine-uwmc>
 - ▶ See link on left for specific care providers.
- ▶ Harborview Medical Center Rehabilitation Medicine/Rehabilitation Psychology (staff include PT, OT, SLP, clinical psychology)
 - ▶ <http://www.uwmedicine.org/locations/rehabilitation-medicine-harborview>
 - ▶ See link on left for specific care providers.
- ▶ Northwest Hospital Stroke Program
 - ▶ http://www.nwhospital.org/services/stroke_main.asp

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Resources for Getting Help

- ▶ Evergreen Health—Dr. Kristen Sherman (rehabilitation psychologist focusing on disability and relationships, sexuality)
 - ▶ https://www.evergreenhealth.com/search/physician_profile/kristen_sherman_phd
- ▶ Psychology Today—therapist search
 - ▶ <http://therapists.psychologytoday.com/rms/county/WA/King.html>

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