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Sexuality and Stroke: How to Help Patients When Intimacy Changes

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Today's objectives

1. Describe patient interventions and modifications used to increase independence of the post-acutes stroke patient as it relates to mobility, ADL's, and communication.

2. Gain knowledge on research outcomes about sexuality and stroke

3. Identify the PLISSIT Model and how the components can help provide care to stroke patients

4. Describe three specific tools/resources to help stroke patients increase healthy sexual sense of self

World Health Organization (WHO)

According to the current working definition, sexual health is:

"...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.**"

(World Health organization)

What Does Post-Stroke Research Tell Us

Reported facts about Sexual functioning post stroke

-Patients who have sustained a rights hemispheric stroke have been shown to suffer a significantly greater amount of sexual dysfunction. (Coslett et al)

-If stroke occurs in the frontal lobe, the survivor may feel less inhibited and less aware of socially appropriate sexual behavior

-A majority of stroke patients reported decline in libido, coital Frequency, erectile and orgasmic ability and vaginal lubrication (Korpelainen et al)

-Pain during sexual activity, fatigue, anxiety/depression and body image are also often listed by stroke survivors

Study on Cardiac Nurses and Sexual Counseling of Patients

- **Objective**: To examine trends in the practice of sexual counseling by cardiac nurses
- **Method**: Took survey in 1994, n=177 and 2009, n=288
- **Results**: Nurses in 2009 sample reported greater sense of responsibility for providing sexual counseling then those in 1994 survey
- Although sexual activity (Cuddling, Kissing, Fondling, Masturbation and Oral sex) were discussed more frequently by the nurses in 1994
- Lack of knowledge and preparation to provide sexual counseling in practice seems to be an ongoing issue noted in both early studies and more recent work

(Steinke, et al)

Study out of Canada on improving sexual health for patients in stroke rehabilitation

- 10 month project using a Plan-Do-Study-Act methodology
- Problems found: **No standardized point during rehabilitation stage was sexual health discussed, No clear ownership of which discipline would cover the topic**
- During 3 month pre project data collection showed (10-15 patients entered facility a month) that **0/30 (patient feedback) were given opportunity to discuss sexual health**
- **Occupational therapist** felt that they could implement questions during their intake and that they felt this was in their scope of practice

(Guo et al., 2015)

Study out of Canada on improving sexual health for patients in stroke rehabilitation (Continued)

- **Script was formed, had four components**
- 1) **Normalize**: "Often people after stroke have concerns about sexual functioning, intimacy and relationships."
- 2) **Give Examples**: "For example, people might have questions like 'Is it safe for me to go back to intimate and sexual activities with my partner?"
- 3)**Offer to listen to patients" concerns**: "We want to help you because sexual health is an important part of being healthy and having a good quality of life. Do you have any concerns right now" if no answered reminded they could bring up later in their rehab.
- 4) **Inform patients of other resources that they can access to learn about sexual health and stroke**

(Guo et al., 2015)

Study out of Canada on improving sexual health for patients in stroke rehabilitation (Results)

- Aphasia Patients missed and were then addressed by Speech providers using a supported conversation tool
- Patients tended to bring up sexual health concerns later in their stay
- Increase from baseline of 0% to 80% by end of the project
- Small sample size but place to start for more research in this area

(Guo et al., 2015)

Research on Perspectives on Poststroke Sexual Issues and Rehabilitation

- Method: Semi-structured interviews completed with 15 survivors and 14 partners of stroke survivors from Minneapolis, MN area. A qualitative thematic analysis was done to find a pattern in themes.

- Results: Seven themes were identified, 5 related to addressing sexual concerns and 2 to the effects of stroke

(Schmitz M, et al)

Two Related to effects of Stroke on sexual life:

1) Physical/Functional Changes

- -Most cited a decrease in sexual desire
- -Fear of isolation
- -Frustration over cognitive changes
- -Lacking confidence in self
- -Still a strong need for touch and emotional connection

2) Relationship Changes

- -Caretaker vs. Spouse/partner (Role changes)

(Schmitz M, et al)

Five related to addressing sexual issues in the process of Rehabilitation:

1) Difficulty talking about sex

- Patients affirmed sexuality was vital part of their lives
- General discomfort talking about sex

2) Little to no discussion on post stroke sexuality

- Only 1 out of 29 participants reported their medical team discussed sexuality
- Many felt rehab team should initiate discussion about poststroke sexual adjustme
- Patient's partners acknowledge there may be a lack of education or experience

3) Need to tailor education to an individual or a couples needs

- Wanted to know more about safety of having sex after stroke
- Most wanted a written handout about communicating

(Schmitz M, et al)

- 4) Timing of Poststroke sexual education

- Many participants felt that the best time to discuss sexual adjustment issues within the rehabilitation process would be likely toward the end of acute hospitalization or shortly after going home

- 5) Provide rapport and competence is vital to discussing sexual issues

- Expect professional regardless of area of specialty have the personal and professionals skills to establish rapport with patients
- Providers ability to establish rapport was viewed as a precondition, a perception of competence was considered fundamental as well.

- Conclusion: Studies like this strongly suggests that stroke survivors and partners need help and support in dealing with sexual issues after stroke

(Schmitz M, et al)

Limited Research how stroke changes the experience of sexuality among LGBTQI+ community

Study Completed in Australia in 2022-

- Some members of this community are at a higher risk of stroke particularly transgender women using HRT (Hormone Replacement Therapy).
- Fear of bringing these issues up to their health care teams due to homophobia, transphobia and heterosexism in health settings
- Interventions after stroke with Gay men have primarily been focused on penis in anus activities and avoidant of their other types of sexual play

Limited Research how stroke changes the experience of sexuality among LGBTQI+ community (Continued)

- Some stated they moved to ethical non-monogamy to support the sexual needs of their partner (Opened up their relationships)
- Often stated that positions (Tops/bottoms role and solo sex) familiar to them had to be shifted due to loss of ability in parts of their body and solo
- The LGBTQI+ community was seen as a safe and inclusive place for individuals prior to their stroke but after this was not the case. Shows the challenges of intersecting forms of discrimination on the challenge of holding multiple minoritized identities.

More research needed in this area to help support inclusion

More reasons we should care…….

- People are living longer. Vast majority of Stroke patients survive.

- Pleasure and Sexual expression seen as more important part of a person's life

The Sexual Response Cycle

Originally developed by Masters and Johnson in the 1950’s

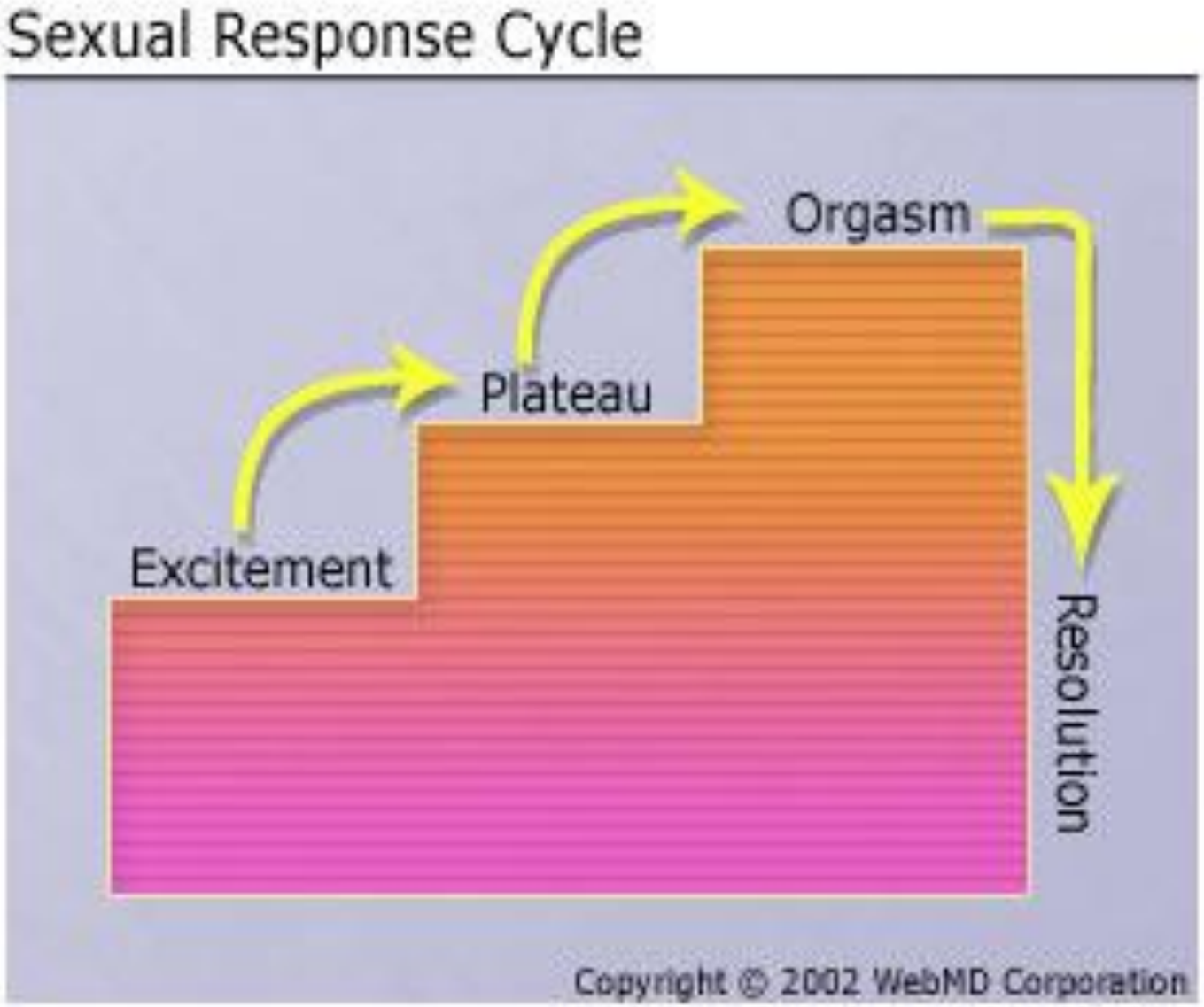
Has evolved over time through research

Men and Women are different in sexual response (Original thoughts)

Four/Five Stages: (Desire), Excitement, Plateau, Orgasm, Resolution

(*Human sexual response cycle* 2024)

Male


Sexual Response Cycle
Orgasm
Plateau
Excitement
Resolution
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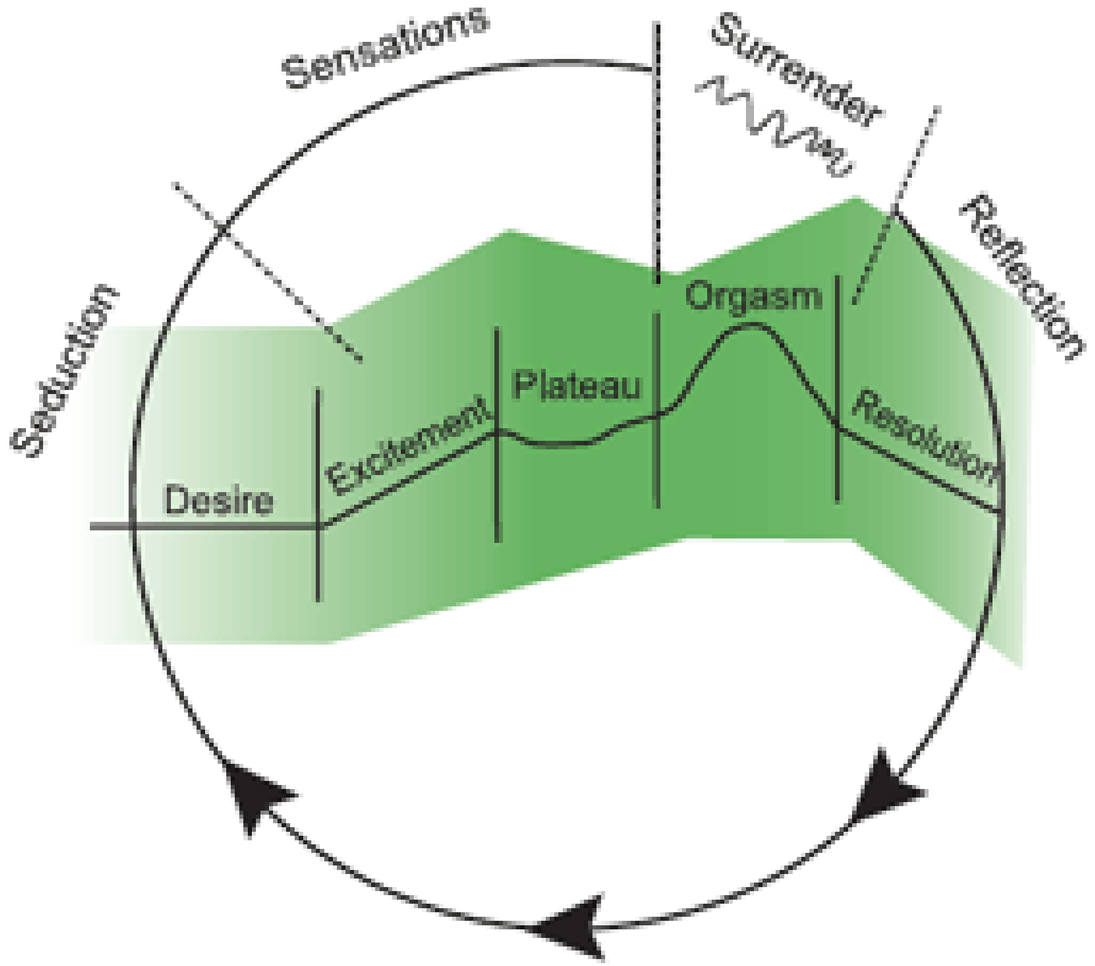
Female

FIGURE 2. Circular Model of Female Sexual Response Developed by Whipple and Brash-McGreer[5]



Whipple and Brash-McGreer's circular model of female sexual response shows how pleasure and satisfaction during one sexual experience can lead to the seduction phase of the next sexual experience.

Some Myths about Sex and Disability

- Individuals living with disabilities are not sexual
- Sex must be **spontaneous**
- Individuals with disabilities are often thought of as child like forever and have other things to worry about
- Disabled individuals can not control their sex drives (Compulsivity issues depending on part of the brain effected)

(Silverberg, 2016)

Communication Needs

Biggest Sex organ is the brain

Most of overvalue talking and undervalue all the other movements; facial expressions, moaning, gazing and laughing

ACC devices may not have all language needed and wanted (sexual arousal devices and sexual words). Also tone may not match the individual

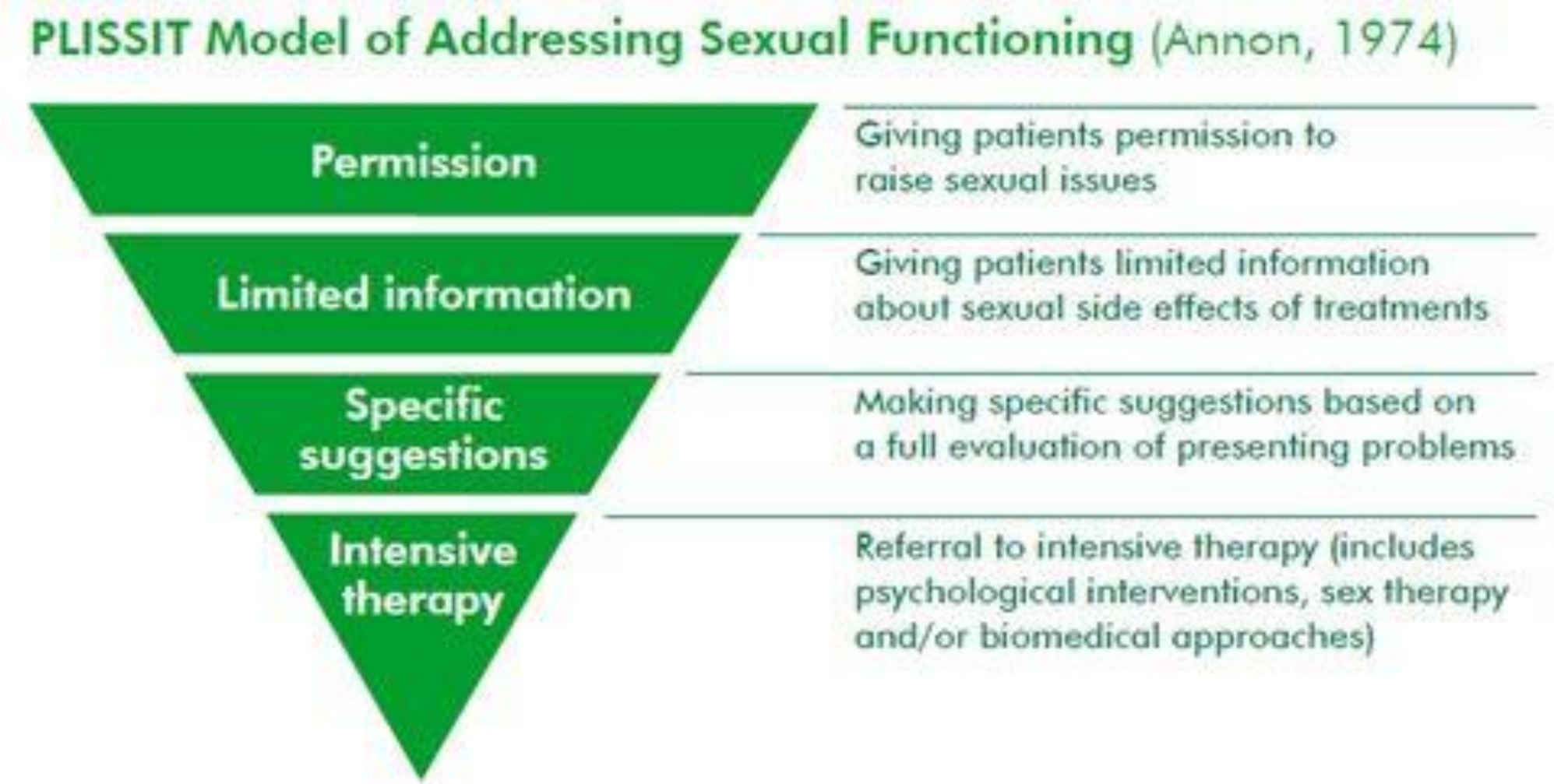
Often Needs, Desires and requirements get muddled, someone might require help with undressing or getting in certain positions and asking a partner can be uncomfortable but a requirement.

(Silverberg, 2016)

Why is consent so important?

- First Evaluate if the individual can comprehend through intellectual properties what sexual consent is.
- Some states say if have intellectual disability then they can not consent to sex
- How much does this effect privacy with a person’s sexual needs/desires
- A lot of the time straight questions deserve straight answers.

How to help patients get the information they want



Where to Start?
Permission

- Ask/Give permission to discuss the topic
- Mention that the presenting condition may impact sexual activity
- Listen to words, tone and body language
- Be direct, but appropriate with language
- Feel **personally comfortable** or don’t bring it up

Sexual History Taking

"Now I am going to ask you some questions about your sexual health. I ask these questions of all my patients regardless of age, sex, gender or partner status and they are just as important as other questions about your physical and mental health. Like the rest of this visit, this information is strictly confidential."

- tweaked from the California Department of Public Health

Providing Limited Information

- Sexual Response Cycle factors
- Anatomy and Physiology
- Effects of illnesses (sensory and perceptual)
- Effects of Medication
- Role Changes
- Anxiety and Depression (Rejection and performance)
- Resources- social/relationship groups and adult self care skills
- Birth control options, to not increase blood clots

Specific Suggestions to improve sexual functioning

- Timing: Early morning, in relations to medications and fatigue
- Empty bladder before sexual activity
- Communicating needs and wants to your partner openly with out being defensive
- Being open to changing “Normal” sexual routine (Scripts)
- Positional Changes- alternate positions
- Counseling (Marital/Relationship/Individual/Sexual)

Viagra, Cialis and Levitra

Erectile Dysfunction medications to increase blood flow

Vyleesi 2019

Similar to Prozac not Viagra. It works with brain chemicals. Injection prior to sexual activity.

Intensive Therapy Suggestions

Types of Touch

1. **Affectionate Touch**
   Holding hands, kissing, hugging

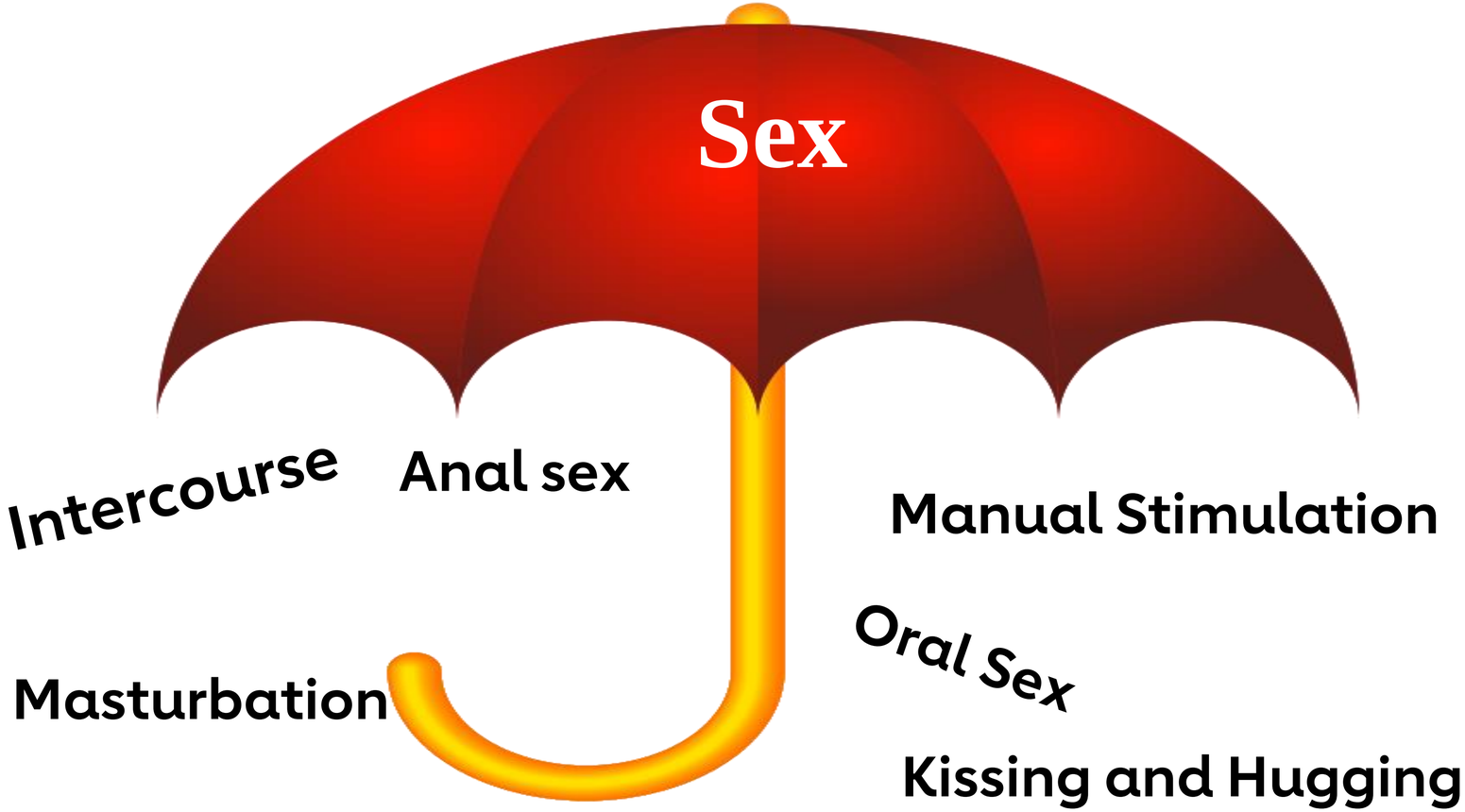
2. **Sensual Touch**(clothed or not)
   Cuddling, massage, showering together

3. **Playful Touch**
   In bed, dancing, on the couch

4. **Erotic Non-Intercourse Touch**
   Manual, oral, or rubbing

5. **Erotic Intercourse Touch**
   Penetration

Reframing the Word Sex



Grief

- The need to grieve the loss of the previous sexual self and learn to accept the current

- Stages of Grief: Denial, Bargaining, Anger, Depression and Acceptance

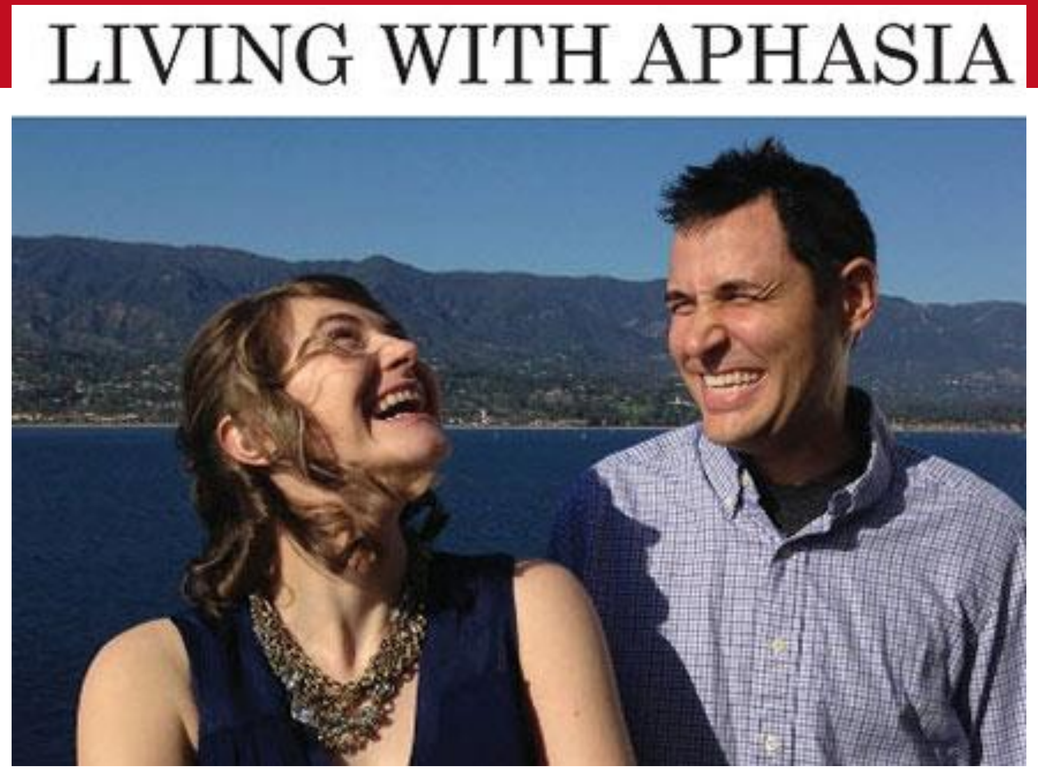
- “Grief is a lot of questions with no answers”

Role Changes

- Start slow (Explore sensations)
- Open Communication about Fears and Wants
- **Changes in who initiates** sexual activity or touch
- Often needs to be brought up by survivor due to fear of offending
- Nonsexual touch just as important if not more then sexual touch

Aphasia

- Many ways to communicate
- Non verbally- forces to be present
- Touch, Caress, Gestures
- Can be difficult adjustment
- **GO SLOW!**
- 2 minute hug helps with oxytocin, serotonin and dopamine- makes us feel good



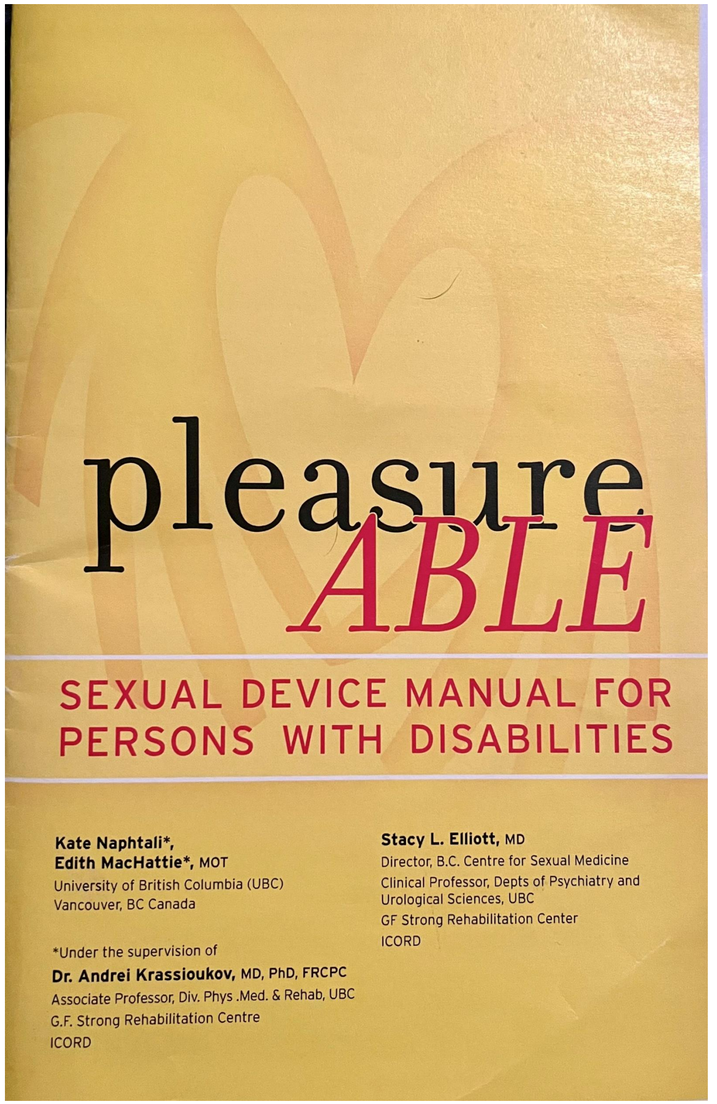
Incontinence

- **Very common problem**
- Limit fluids
- Use bathroom before activity
- Avoid positions that put pressure on bladder
- Use of plastic sheets or mattress protector.
- Try bath or shower play

Paralysis

- Try using pillows/wedges to help
- Keep **experimenting** till find something comfortable
- One side weaker then the other so need to use alternate positions or accommodating furniture
- Position Changes – OT hand out by Herman and Wallace

Websites and Manuals



Specific products that might help the patient and/or their partner

- Dilators

- Arousal Devices

- Arousal Creams

Body Image issues

- Hemiplegia (paralysis of one side of the body)
- Drooling
- Facial drops
- Speaking changes
- Increasing self esteem has major impact on change

Partners

- Remember they are also in a stage of adjustment
- Some become overprotective
- Some don’t want to pressure partner who had the stroke
- Others need more time to process what is happening (own therapy)

Single and Sex after Stroke

Practice what you are comfortable sharing and when with a potential partner

Online (Support groups) or local resources are helpful to find others seeking how to adjust after stroke and re-entering the dating world.

Collaboration is key

"Alone we can do so little; together we can do so much." - Helen Keller

- One of the most important outcomes that we see in our patients is when their whole team is working together
- Need to address the major parts of the patient: Medical, Physiological, and Psychological
- This is not always easy due to the complex nature of sexual issues as well as the treatment team is usually across organizations, private practice and many different disciplines.

Additional Resources

- Association of Sex Educators, Counselors and Therapist (www.aasect.org)
- Book: The Ultimate Guide to Sex and Disability by Miriam Kaufman, M.D., Cory Silverberg and Fran Odette
- Diverse City Press: www.diverse-city.com (Excellent Resources for all ages)
- The Speak Up Project
  - This group developed picture and word vocabularies for those that use augmentative and alternate communication.
- Online: www.comeasyouare.com/sex_and_disability
  - Help with making sex toys accessible

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