“Just the Way You Are”: Sex and Intimacy After Stroke

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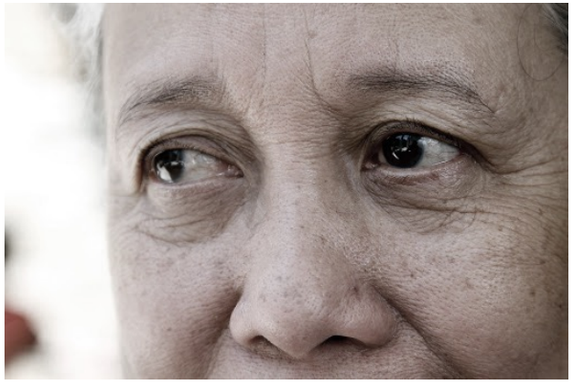
OBJECTIVES

- Explore changes and challenges with sexual activity and intimacy after stroke
- Learn how to address sex and intimacy with patients and their partners

CASE STUDY: "FRAN"

- 59 y.o. woman
- LH ischemic stroke
- 6 months post
- Seen in outpatient clinic for follow-up



Stroke affects sexuality in more than 50% survivors and can lead to many sexual difficulties, such as erectile dysfunction, loss of vaginal lubrication or a decrease in desire.

"Acquired physical and mental impairments may significantly alter, yet do not eliminate basic sexual drives or human needs for affection, intimacy, and a healthy positive self-concept" (Medlar, 1998)

UNDERSTANDING PHYSIOLOGICAL AND PSYCHOLOGICAL CORRELATES OF YOUR PATIENT'S STROKE CAN HELP TO ANTICIPATE AND EFFECTIVELY TREAT CO-OCCURRING SEXUAL DYSFUNCTION

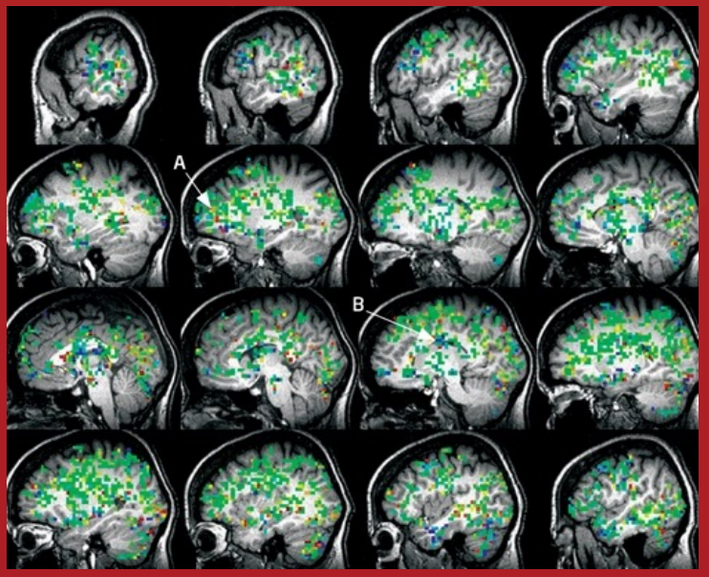
Physiological Correlates
(direct effects)

- Site of brain injured in stroke
- Neurochemical changes
- Hemiparesis
- Sensory changes
- Premorbid/comorbid medical complications

Psychological Correlates
(indirect effects)

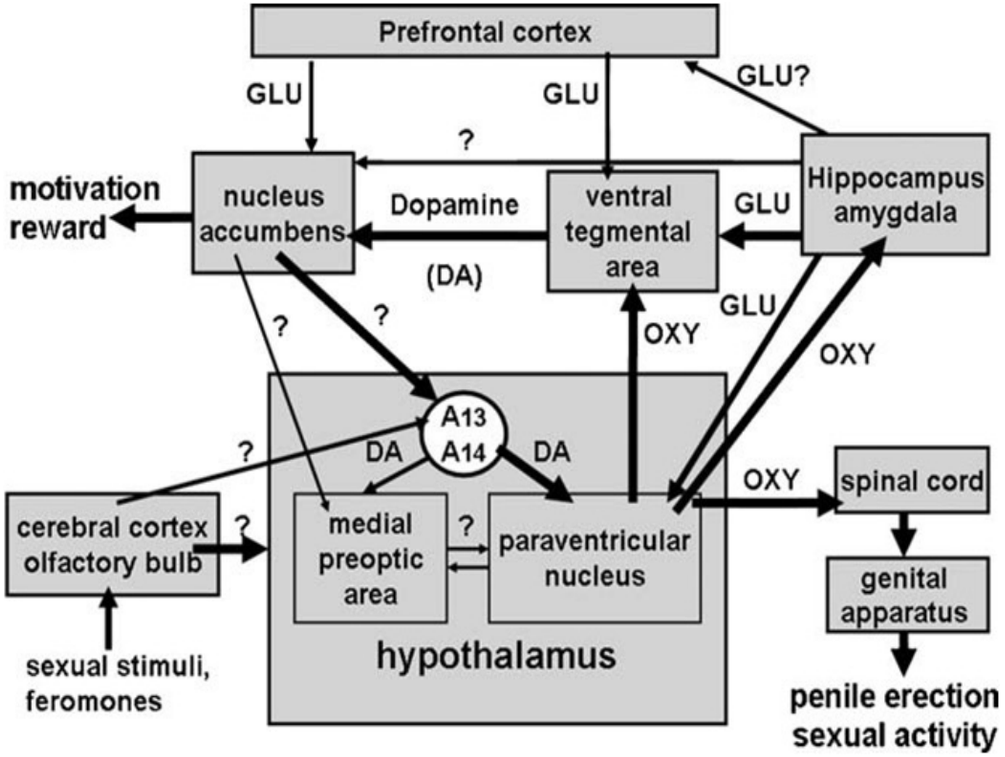
- Mood/adjustment disorders
- Behavioral changes
- Communication changes
- Changes in psychosocial dynamics (the couple)

The Most Important Sex Organ: The Brain

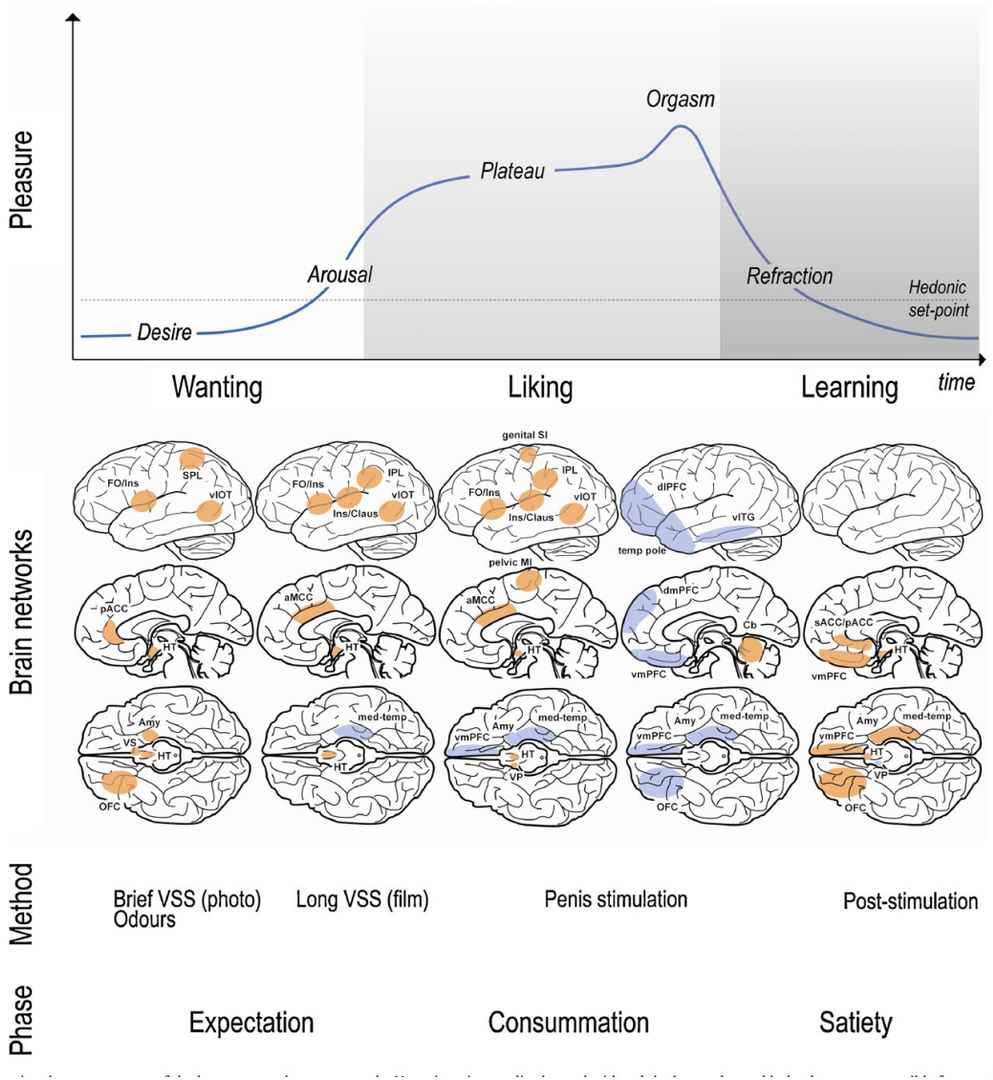


AREAS OF BRAIN ACTIVATION DURING AND AFTER SEX

- Hypothalamus
- Midbrain
- Amygdala
- Hippocampus
- Anterior cingulate
- Frontal, parietal, temporal, and insular cortex
- Anterior basal ganglia (basal forebrain- nucleus accumbens)
- Cerebellum



WHAT HAPPENS TO THE BRAIN BEFORE, DURING, AND AFTER SEX?



Georgiadis, J.R., & Kringelbach, M.L. (2012). The human sexual response cycle: Brain imaging evidence linking sex to other pleasures. *Progress in Neurobiology, 98*, 49-81.

DIFFERENT STROKE LOCATIONS CAN IMPACT DIFFERENT ASPECTS OF SEXUALITY

Left hemisphere

- Hyposexuality
- related to depression

Right hemisphere

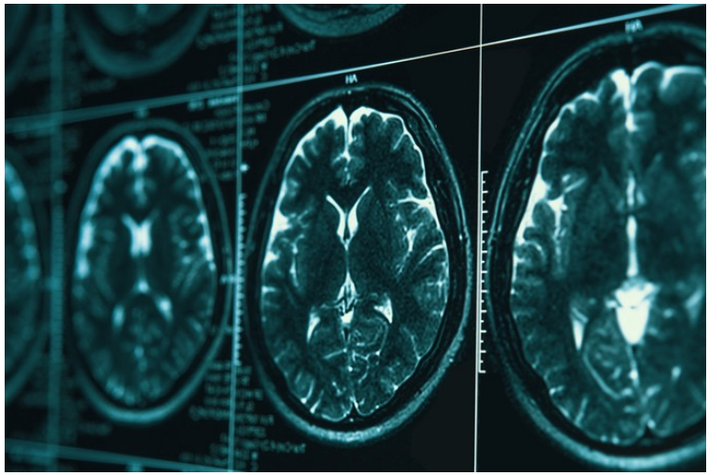
- Hypersexuality
- related to a loss of inhibition and regulation

Front of the brain

- Motivation to engage in sexual activity
- Decreased sexual arousal
- The ability to initiate sexual activity
- Impulsive or inappropriate sexual activity
- The production of language and ability to communicate

Rear of the brain

- Awareness of issues that need to be addressed - neglect
- The understanding of language and ability to communicate



HEALTH FACTORS THAT IMPEDE SEXUAL FUNCTIONING

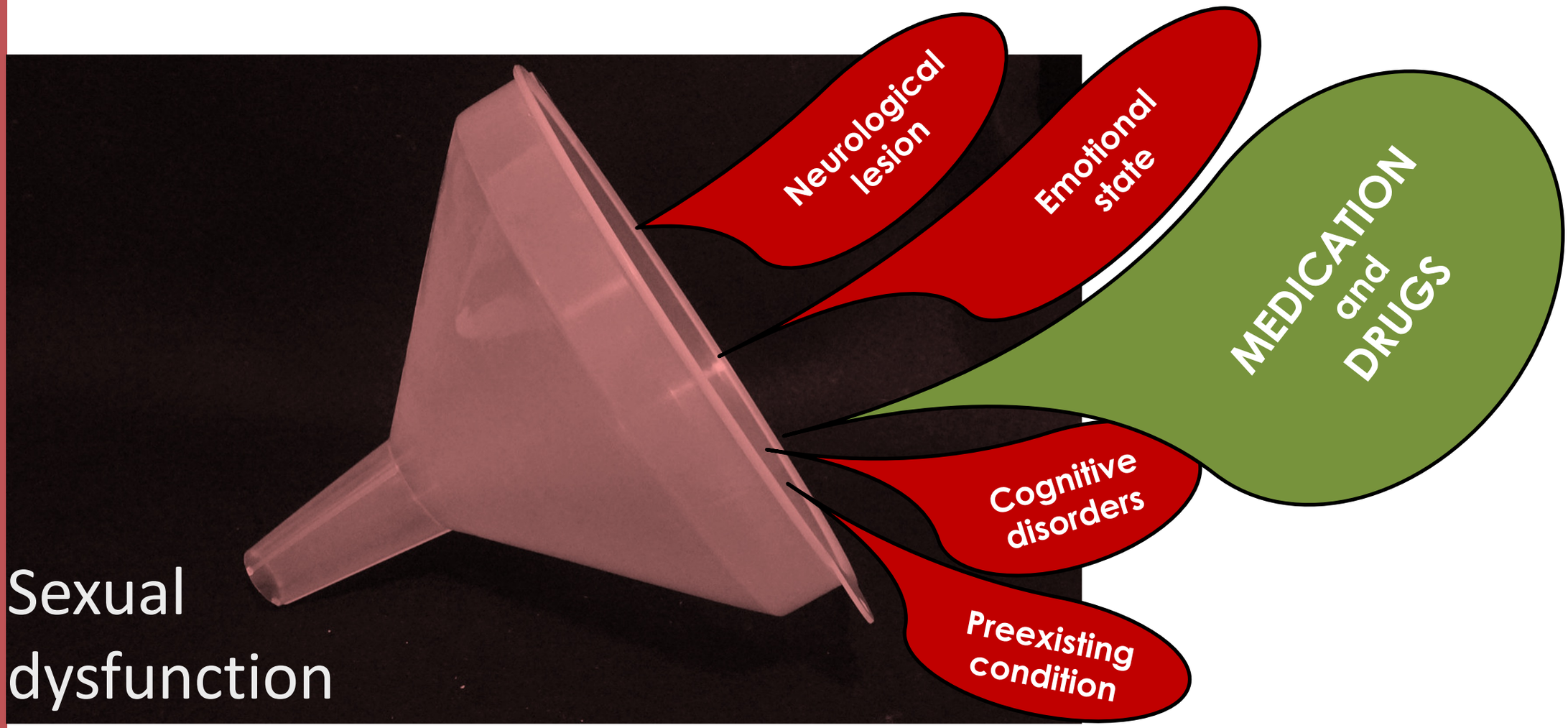
- Reduced blood supply to sexual organs – 80% of strokes are ischemic
  - Atherosclerosis
  - Hypertension
  - Diabetes
- Hormonal changes
  - Reduced testosterone
  - Reduced estrogen and progesterone
  - Reduced thyroid hormone
- Bowel and bladder issues

HEALTH FACTORS THAT IMPEDE SEXUAL FUNCTIONING: DEPRESSION

- Depression very common after stroke
  - Reduced libido is one of the hallmark symptoms of depression

- Fear of stroke during sex. Very low likelihood except with aneurysm.

MEDICATION CONSIDERATIONS



Sexual Relationships & Intimacy

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"My body doesn't look the way it used to"

"I don't know if it's okay for us to have sex"

"I worry I will have another stroke"

"My body doesn't work the way it used to"

"I worry you will have another stroke"

"I'm not sure I can perform"

"I need to constantly keep an eye on you to keep you safe"

"I feel unattractive"

"I'm being treated like a child"

"Your personality is different since the stroke"

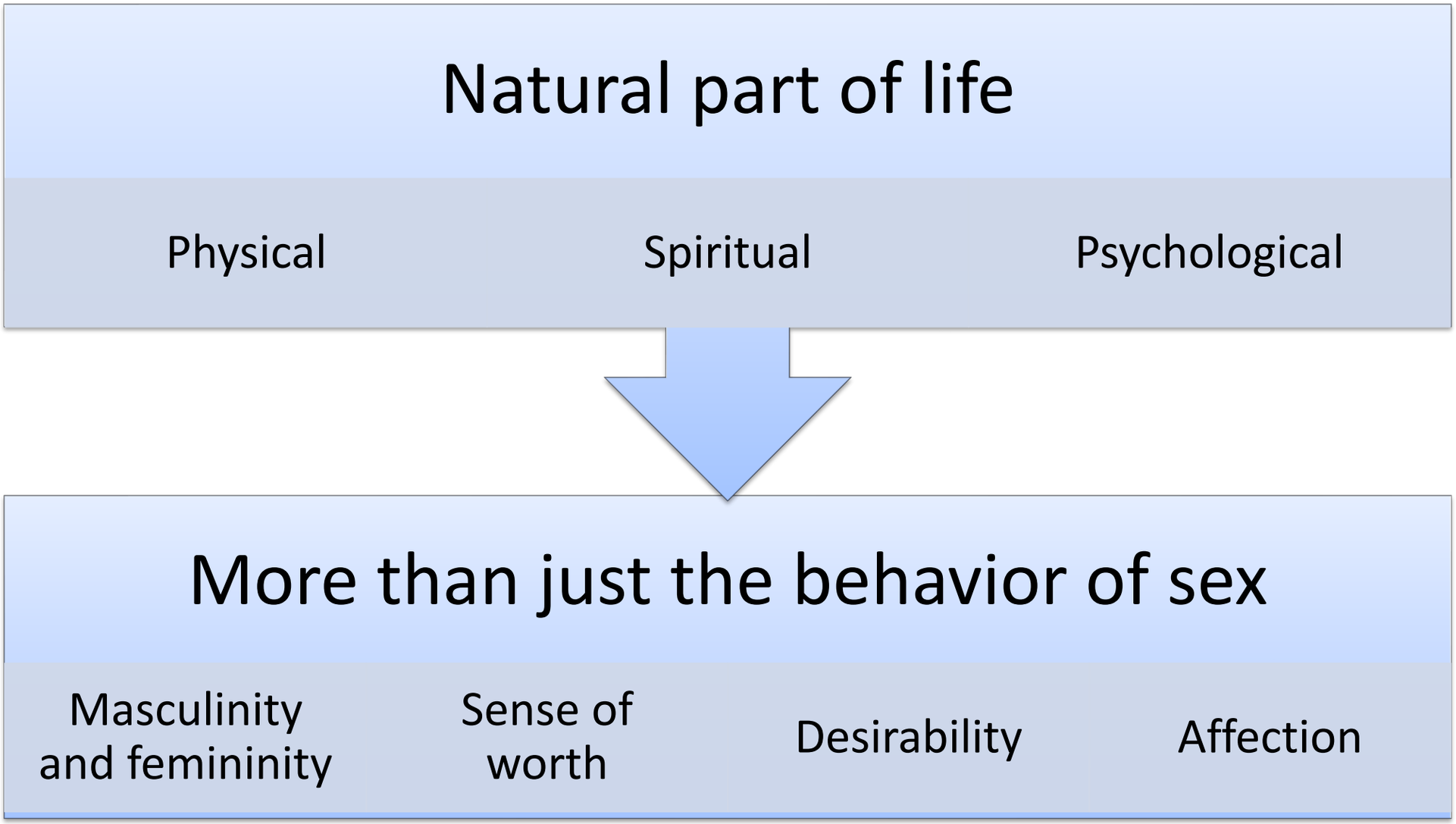
"I had to get a second job to support us"

"I feel like a burden"

"I am unable to provide for the family"

"I feel like a parent, not a partner"

SEXUALITY



INTIMACY

- Create and sustain intimate relationships
- Intimacy with and without sex
  - Quality time
  - Verbal expressions of love
  - Warmth and closeness with and without touch
  - Physical intimacy

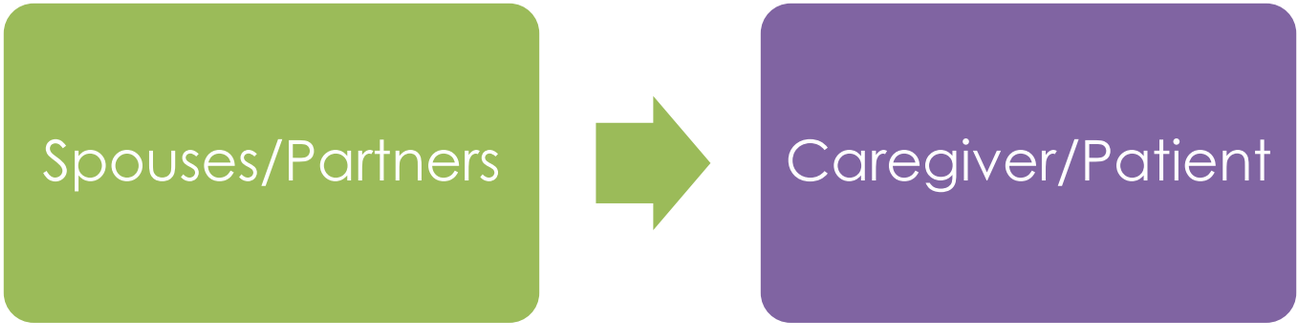
INTIMACY FACTORS (GILL, 2011)

- Unconditional, unselfish love
- Being present
- Commitment to staying and working on the relationship
- Communication
- Being understanding
- Preinjury relationship foundation
- Grateful for survival
- Spending time together
- Social support
- Family bonds

What gets in the way?

CHANGES IN ROLES

- Changes in roles are common following a stroke for the survivor and their partner
  - New roles: caregiver, reassignment of household tasks
  - Role losses or reversals (e.g., primary provider is no longer able to work)



New roles are often dissonant with sexual and romantic roles

McGrath et al., 2018

SELF-IMAGE

Changes in physical and sexual functioning

Sex & Intimacy

Shame, frustration, depression

Confidence and sense of self

Changes in body function, body image, and self-esteem can occur after a stroke, interfering with sex and intimacy

(McKevitt et al, 2004; McGrath et al., 2019; Schmitz & Finkelsten, 2010; Shah & Hillinger, 2015))

PARTNER PERCEPTIONS

The partner may:

- be bothered by some of the effects of the stroke
- have a more negative appraisal of survivor's physical and cognitive functioning
- be over-protective/parental toward survivor, leading to frustration in the survivor

(Kautz et al., 2009; McCarthy et al, 2012; Niermeyer et al., 2022)

COMMUNICATION AND COGNITIVE IMPAIRMENT

- Conditions with cognitive impairment and aphasia are among the most difficult for couples
- May seem like a different person to their partner/spouse → transformed relationship
- Communication critical to intimacy
- One partner may lose sexual interest (or experience guilt regarding their own unmet sexual needs)
- Sexual desire often remains intact despite loss of cognitive abilities

Daniels et al., 2009; McGrath et al., 2019; Rolland, 2018

COGNITIVE IMPAIRMENT

- … and the issue of mutual consent
- Stroke survivor may be either painfully aware or lack insight into impairment
- Clinicians should be on the lookout for concerns of abuse
- Communication is key

Assessment and Treatment

RECOMMENDED APPROACH TO SEXUALITY IN HEALTHCARE:

- Sexuality is a valid health issue that should be addressed in all clinical settings.

- Sexuality should be dealt with in the same manner as other important issues in health care.

HCP's PLAY A VITAL ROLE IN ACCOMPLISHING THIS MISSION!

YOU KNOW YOUR PATIENTS INTIMATELY (PHYSICALLY AND EMOTIONALLY)

THIS RAPPORT IS A THERAPEUTIC TOOL!

BARRIERS TO ADDRESSING SEXUAL FUNCTIONING

- Lack of clarity of who's role it is
- Lack of knowledge & confidence
- Uncertainty whether anything can be done
- Fear of offending the patient or making them feel worse about their condition
- Lack of time
- Assumptions (e.g., pt too ill, pt older, does not have a partner); stigma about disability
- Cultural/personal bias

SO WHERE DO WE BEGIN?

- Maintain an honest, open and professional approach. Don't apologize or act skittish when bringing up the topic.
- Ensure that you are properly educated about how stroke impacts sexuality

- Your job to facilitate:
  - Health promotion
  - Remediation
  - Modification
  - Overall health and wellness

Be aware of your own biases. If you feel that you can't have these important conversations, make sure that you utilize another member of patient's treatment team who can.

FOR STARTERS….

- Interview should begin with general inquiry and move into more sensitive areas
- Use **bridge statements** to incorporate sensitive or difficult topics into the interview.

Examples :

  - To what extent are you satisfied with your sex life?
  - Has anyone talked to you about how your stroke can affect your ability to have sex or be in a sexual relationship?
  - Since your stroke, has your relationship with your partner changed? Do you have concerns about your safety or communication with your significant other?
  - Has your libido or interest in sex changed?

ASSESSMENTS

- The Quality of Life After Brain Injury Questionnaire

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5

ASSESSMENTS

- Sexual Interest and Satisfaction Scale

Areas	Questions	Scale Points	Scale Score (0 – 3)
1. Sexual desire	How is your sexual desire now compared to before injury?	Non-existent (0) Decreased (1) Unchanged (2) Increased (3)	
2. Importance of sexuality	How important is sexuality to you now compared to before injury?	Non-existent (0) Decreased (1) Unchanged (2) Increased (3)	
3. General satisfaction with sex life after injury	How is your relationship, most of the time, with your sexual partner after injury?	VAS scale*: 1- very dissatisfying 7- very satisfying	Reported score*: _____ Scale score:
4. General satisfaction after injury compared w/ before injury	How was your relationship, most of time, with your sexu partner before injury Subtract the pre-inju VAS score from the V score (1-7) in item #		

- Changes in Sexual Function Questionnaire Short Form (CSFQ-14)

CHANGES IN SEXUAL FUNCTIONING QUESTIONNAIRE (CSFQ-F-C)

Patient Name _____ Today's Date _____

NOTE: This is a questionnaire about sexual activity and sexual function. By sexual activity, we mean sexual intercourse, masturbation, sexual fantasies and other activity.

1. Compared with the most enjoyable it has ever been, how enjoyable or pleasurable is your sexual life right now?
☐ 1-No enjoyment or pleasure
☐ 2-Little enjoyment or pleasure
☐ 3-Some enjoyment or pleasure
☐ 4-Much enjoyment or pleasure
☐ 5-Great enjoyment or pleasure

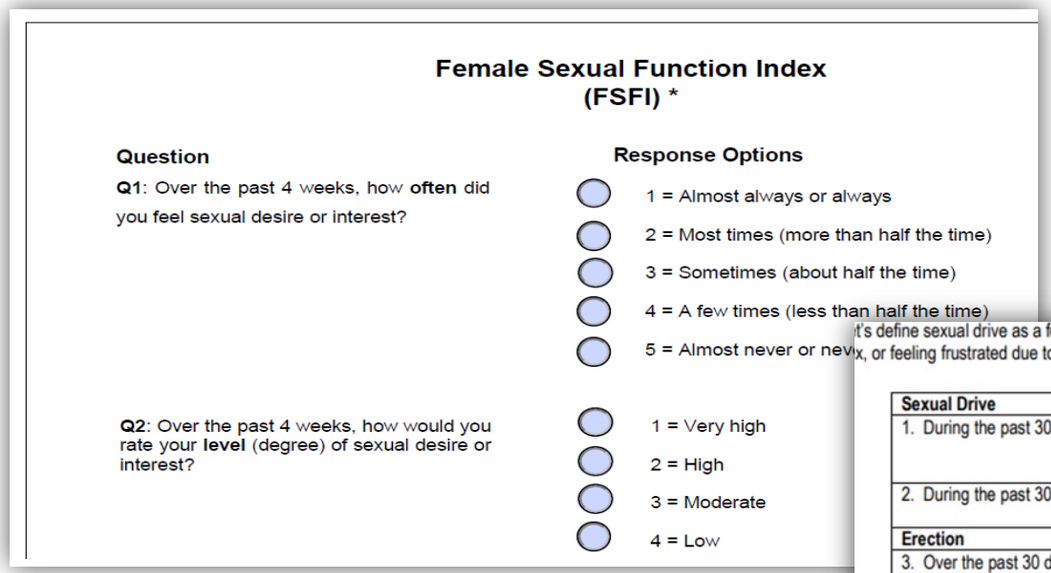
2. How frequently do you engage in sexual activity (sexual intercourse, masturbation, etc.) now?
☐ 1-Never

8. Are you easily aroused?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

9. Do you have adequate vaginal lubrication during sexual activity?
☐ 1-Never
☐ 2-Rarely (much less than half the time)
☐ 3-Sometimes (about half the time)
☐ 4-Often (much more than half the time)
☐ 5-Always

ASSESSMENTS

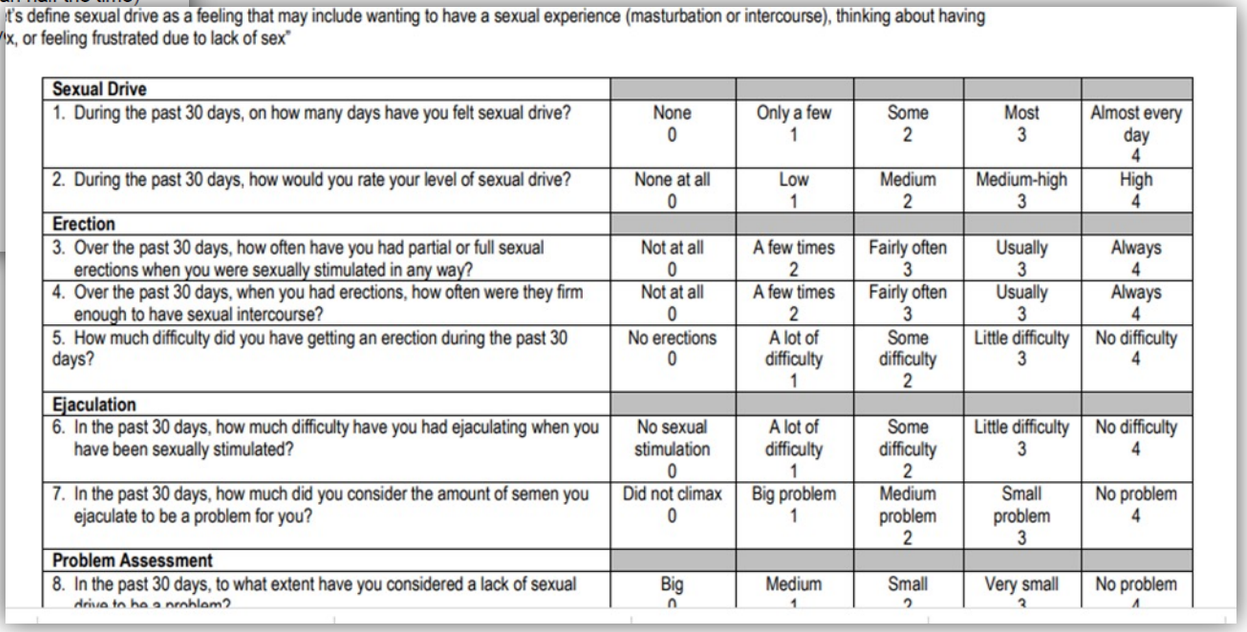
- Female Sexual Function Index



Female Sexual Function Index (FSFI) *

Question	Response Options
Q1: Over the past 4 weeks, how **often** did you feel sexual desire or interest?	1 = Almost always or always 2 = Most times (more than half the time) 3 = Sometimes (about half the time) 4 = A few times (less than half the time) 5 = Almost never or nev
Q2: Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?	1 = Very high 2 = High 3 = Moderate 4 = Low

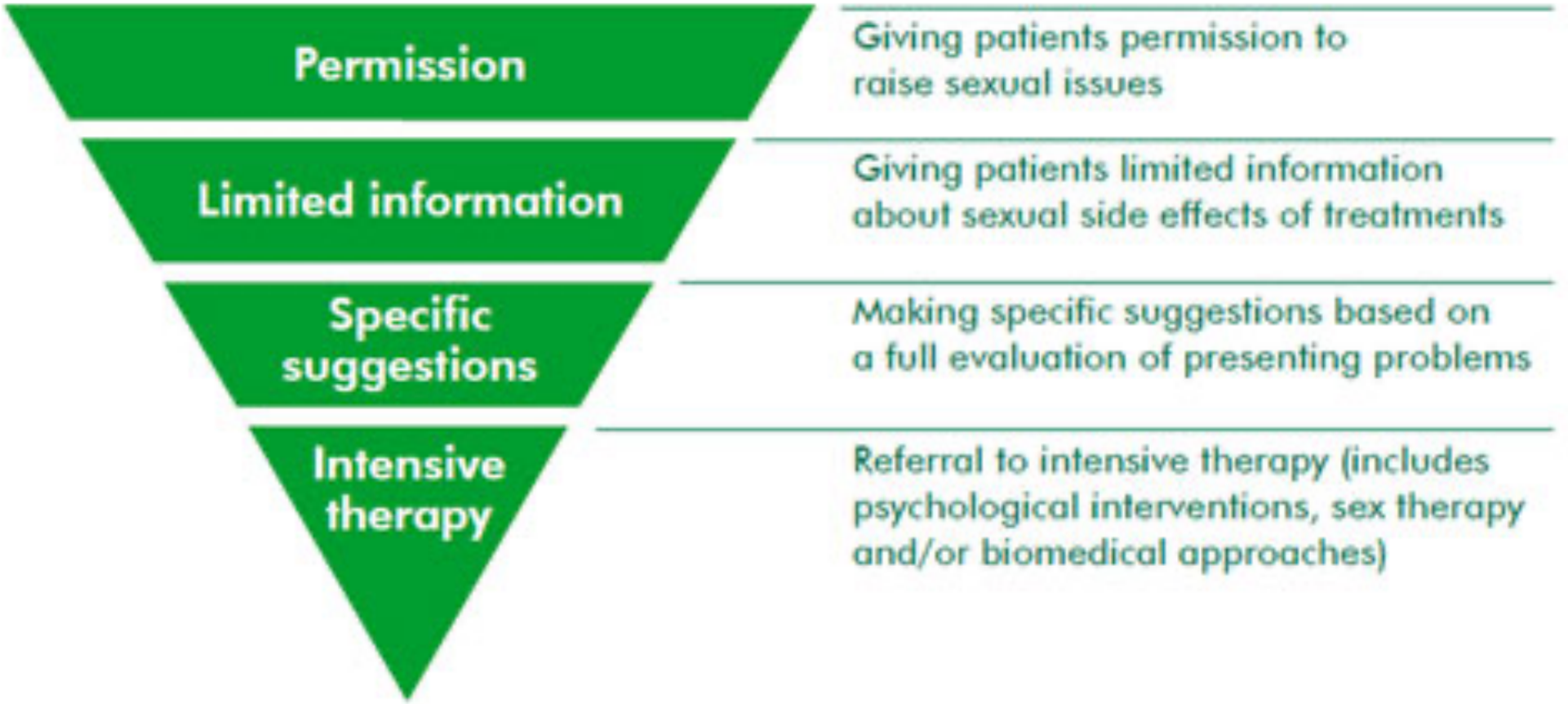
- Male Sexual Function Index



t's define sexual drive as a feeling that may include wanting to have a sexual experience (masturbation or intercourse), thinking about having x, or feeling frustrated due to lack of sex"

Sexual Drive					
1. During the past 30 days, on how many days have you felt sexual drive?	None 0	Only a few 1	Some 2	Most 3	Almost every day 4
2. During the past 30 days, how would you rate your level of sexual drive?	None at all 0	Low 1	Medium 2	Medium-high 3	High 4
Erection					
3. Over the past 30 days, how often have you had partial or full sexual erections when you were sexually stimulated in any way?	Not at all 0	A few times 2	Fairly often 3	Usually 3	Always 4
4. Over the past 30 days, when you had erections, how often were they firm enough to have sexual intercourse?	Not at all 0	A few times 2	Fairly often 3	Usually 3	Always 4
5. How much difficulty did you have getting an erection during the past 30 days?	No erections 0	A lot of difficulty 1	Some difficulty 2	Little difficulty 3	No difficulty 4
Ejaculation					
6. In the past 30 days, how much difficulty have you had ejaculating when you have been sexually stimulated?	No sexual stimulation 0	A lot of difficulty 1	Some difficulty 2	Little difficulty 3	No difficulty 4
7. In the past 30 days, how much did you consider the amount of semen you ejaculate to be a problem for you?	Did not climax 0	Big problem 1	Medium problem 2	Small problem 3	No problem 4
Problem Assessment					
8. In the past 30 days, to what extent have you considered a lack of sexual drive to be a problem?	Big 0	Medium 1	Small 2	Very small 3	No problem 4

PLISSIT Model of Addressing Sexual Functioning (Annon, 1974)



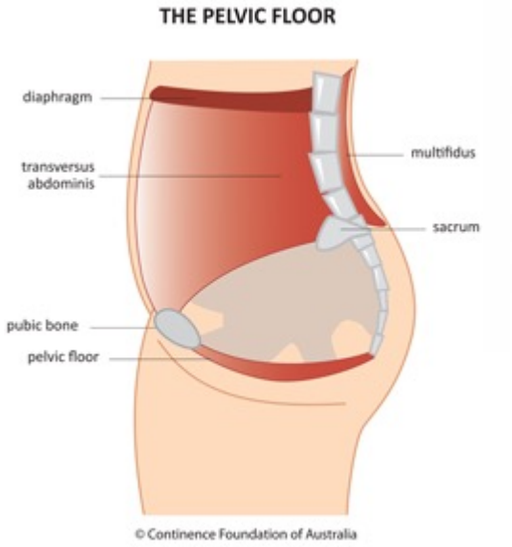
A SEXUAL REHABILITATION INTERVENTION MODEL

Table 2
Contents of sexual rehabilitation intervention

Topics	Contents
1. Information regarding changes in sexual life after stroke	1) Give facts about post-stroke sexuality – Cessation of sexual intercourse in 40% of post-stroke patients – Continuation of sexual activity with decreased sexual frequency and satisfaction in the remaining 60% of post-stroke patients 2) Explain common changes in sexual life after stroke 3) Introduce major causes of changes in sexual life after stroke – Lowered self-esteem and altered body image – Motor paralysis/paresis and sensory loss – Communication difficulty – Altered family relationship
2. General information regarding a healthy sexual life	1) Support to love and support himself/herself 2) Encourage to spend time and have a good conversation with spouse 3) Advise to dispel stereotype views on sexual satisfaction
3. Counseling on fear regarding post-stroke sexual life	1) Discuss fear of causing relapse of stroke, hypertension, or heart disease. Provide accurate information to overcome such fear. 2) Give an opportunity to discuss openly on their difficulties and expectations in sexual life 3) Encourage to discuss about fear of spouse rejection and support to overcome such fear 4) Provide information on diverse sexual behaviors to overcome fear of unsatisfied sexual life
4. Tips and specific strategies to minimize post-stroke sexual dysfunctioning	1) Teach the strategies for initiation of sexual activity 2) Teach the strategies for finding and arranging a suitable time 3) Inform effects of medication currently taken on sexuality 4) Suggest safe and comfortable sexual positions using diagram. 5) Teach how to handle physical, cognitive, and perceptive deficits 6) Teach how to handle decreased vaginal lubrication 7) Teach how to handle urinary incontinence 8) Teach how to handle erectile difficulties 9) Suggest other tips for a healthy sexual life
5. Frequently asked questions and answers about post-stroke sexuality	1) Presenting frequently asked questions and answers regarding post-stroke sexuality 2) Answer any questions or concerns the participants may have.

PELVIC FLOOR MUSCLE TRAINING

- the repetition of one or more sets of voluntary contractions of the pelvic muscles.



Application and Practical Approaches

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WHAT HELPS?

Partners and stroke survivors may have difficulty separating their roles as caregiver and care recipient with roles as sexual partners.

- Hiring someone to assist with care, especially bathing, toileting
- Work with OT to assist with strategies for dressing, toileting, etc

  *slight modifications may greatly increase functional independence (PLUS resumption of sex can be a great motivator to become more independent)

Pierce & Summers, 2015

WHAT HELPS?

- Redefine selves as individuals and as a couple (beyond brain injury & rehab)
  - Playful leisure time as a couple

It brought [us] closer together.. I like the idea that it gave us some things to do so it's helped broaden our perspective on what we can do together.

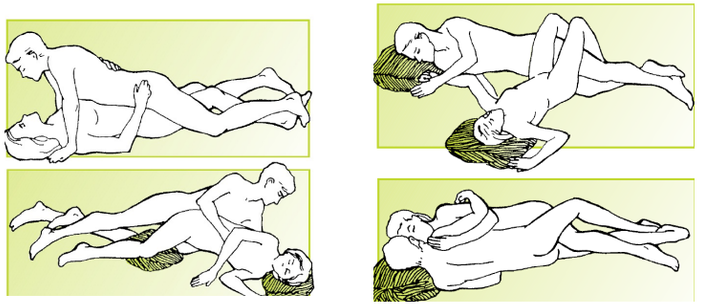
It helped me realize I could enjoy spending time with [my] spouse, not just someone I take care of… feels more like what a marriage or couples would do as opposed to just feeling like I'm a caretaker, which is something that I've struggled with.

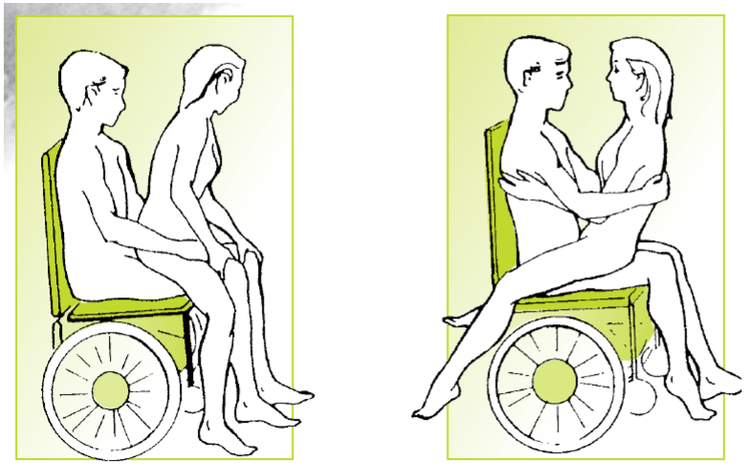
I think we've done a lot more things together...It really just started us picking things to do together and then finding out we enjoyed them so much.

We get along pretty well, we've know each other for 23 years, and I've always loved her, but after the stroke it was hard to express myself and I would get super frustrated, especially about the things that I care deeply about.

POSITIONING

- Patient can receive therapeutic interventions with the assistance of the occupational and physical therapists teaching specific positions that will be conducive to the physical impairments
- If the patient is affected by dizziness and cannot lie flat, prop up with pillows and be on the bottom to help reduce this
- Have the patient lie on their weaker side (supported by pillows) so their stronger side is free
- Partner can assume a more active role in finding comfortable sexual positions





(Australian Stroke Foundation, 2017; Medlar, 1993; MSKTC, 2011; UK Stroke Association 2017

SPASTICITY

- Spasticity can be frustrating for patients trying to engage in intimacy
  - Restrict movement
  - Cause pain
- Plan around medication times, when the medication is most effective
- Lying on the spastic limb and bending it slightly can help control spastic movements of the arms and legs
- Provide gentle passive range of motion, massage, light heat, or vibration prior to engaging in intimacy to help relax spasticity (talk with OT or PT for training)
- If a female has tight thigh muscles, have her lie on her side (can try a pillow between the legs)

(UK Stroke Association 2017

SENSATION CHANGES

- Try using a TENS unit prior to engaging in sexual intimacy (patient should get proper training from a physical or occupational therapist prior to using)
- Try massage or acupuncture
- Engage in some relaxation techniques
- Try de-sensitization therapy (discuss with OT)

BOWEL/BLADDER

- Use the restroom prior to engaging in intimacy
- Use a cover on the bed for peace of mind
- Have the patient lie on his/her side to reduce pressure on the bladder
- Learn how to remove a catheter, or tape it to the side to hold in place

Australian Stroke Foundation, 2017

LUBRICATION AND AIDS

- If the female has vaginal dryness due to a side effect of the stroke, try using a lubrication
- There are a variety of sex toys/aids that patients can buy, both to add in sex with a partner and masturbation (see toolkit for suggested websites)
  - These can help with arousal, compensating for physical changes, and overall enjoyment for the couple or individual
  - Examples: vibrators, gripping aids (for vibrators)
- Website resources:
  - https://disabilityhorizons.com/2014/07/disability-and-sex-lets-be-frank-about-sex-toys/
  - https://www.spokz.co.uk/sex-aids.html

(UK Stroke Association 2017)

ENVIRONMENT

- If the patient requires a low stimulation environment (e.g., gets overwhelmed by noise, colors, lights), make sure to address this with the couple
  - Keep the TV off
  - Dim lights
  - Minimal background noise (if any)

(Headway, 2017; Zellmer, 2016)

APATHY AND FATIGUE

- If the patient is significantly affected by motivation and energy, help the couple plan accordingly
  - Teach energy conservation techniques
  - Choose a time of day where the patient has the most energy (e.g., consider medication side effects, after a nap, in the morning)
  - Engage in calming activities prior (e.g., light massage)

Australian Stroke Foundation, 2017; MSKTC, 2011; UK Stroke Association, 2017; Zellmer, 2016

CASE STUDY: "FRAN"

- 59 y.o. woman
- LH ischemic stroke
- 6 months post
- Seen in outpatient clinic for follow-up

What are factors to consider/think about?

What questions might you want to ask?

Suggested treatment?

HANDOUTS AND WEBSITES

- Headway website
  - https://headwayswindon.org.uk/wp-content/uploads/2021/07/Sex-and-sexuality-after-brain-injury.pdf
- Australian Stroke Foundation
  - https://strokefoundation.org.au/About-Stroke/Help-after-stroke/Stroke-resources-and-fact-sheets/Sex-and-relationships-after-stroke-fact-sheet
- New Zealand Stroke Association website
- Model Systems Knowledge and Translation Center website (University of Washington)
  - https://msktc.org/lib/docs/Factsheets/TBI_Sexuality_and_TBI.pdf
- Sex aids and toys
  - https://disabilityhorizons.com/2014/07/disability-and-sex-lets-be-frank-about-sex-toys/
  - https://www.spokz.co.uk/sex-aids.html

References

Auger LP, Grondin M, Aubertin M, Marois A, Filiatrault J, Rochette A. Interventions used by allied health professionals in sexual rehabilitation after stroke: A systematic review, Top Stroke Rehabil. 2021 28:8, 557-572. doi: 10.1080/10749357.2020.1845014

Dyer K, das Nair R. Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United kingdom. The journal of sexual medicine. 2013;10(11):2658-2670.

McGrath M, Lever S, McCluskey A, Power E. How is sexuality after stroke experienced by stroke survivors and partners of stroke survivors? A systematic review of qualitative studies. Clin Rehabil. 2019 Feb;33(2):293-303. doi: 10.1177/0269215518793483

Ng L, Sansom J, Zhang N, Amatya B, Khan F. Effectiveness of a structured sexual rehabilitation programme following stroke: A randomized controlled trial. J Rehabil Med. 2017;49(4):333-340.

Stead A, White J. Loss of Intimacy: A Cost of Caregiving in Aphasia. Topics in Language Disorders. 2019;39(1):55-70.

Stratton H, Sansom J, Brown-Major A, Anderson P, Ng L. Interventions for sexual dysfunction following stroke. Cochrane Database of Systematic Reviews. 2020(5).