



Government of Western Australia
WA Country Health Service



STROKE 2018
Bridging the Continuum
International Convention Centre, Sydney
7-10 August 2018



Talking about Sexuality

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Feedback from Stroke 2018

September 13, 2018

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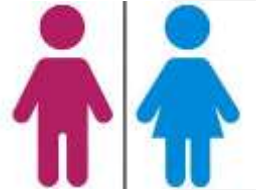
Overview

- Defining sexuality
- Literature review
- The lived experience
- PLiSSiT model
- Resources





What is sexuality?





What is sexuality?

“Sexuality is a central aspect of being human throughout life that encompasses sex, gender, identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. It is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships. It is also influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, historical, religious and spiritual factors”

(WHO, 2002)



Why the focus on sexuality?

“Stroke survivors and their partners should be offered:

- The opportunity to discuss issues relating to sexual intimacy with an appropriate health professional; *and*
- Written information addressing issues relating to sexual intimacy and sexual dysfunction post stroke.

Any interventions should address psychosocial as well as physical function”

Australian Clinical Guidelines for Stroke Management, 2017



Current practice

Only 15% of patients receive information on sexuality post stroke as part of their rehabilitation.

*National Stroke Audit Rehabilitation Services Report 2016
(Stroke Foundation, 2016)*





Literature review

To investigate how stroke survivors report their experience of sexuality.

RESULTS:

- Sexuality is silenced
- Sexuality is still important – muted and sometimes changed, but not forgotten



Sexuality is silenced

*“No, we don’t talk about such things. We talk about practical matters. **No, we never tell each other how we feel. We can’t do that”***

“I have trouble walking with a high heel, and then with a skirt”

*“but it’s a really important thing because, I mean, there are **so many stroke victims that get divorced** it’s frightening actually”*

“Why should a lady want to go out with me if you can go out with someone who doesn’t have a disability?”

*“You’re supposed to be pretty straight and macho... (but)... **I miss being that”***





Muted, changed, but not forgotten



*“Stroke doesn’t change the essence of who I am or what I want... **it only changes what I can do. It doesn’t change what I want**”*

*“every step has to be planned out carefully... **there’s no spontaneity anymore**”*

“I would say it has been for the better. It was good before but it’s really good now, because it’s very tender and loving...”

*“I thought he didn’t want to have intercourse **due to the asymmetric view of my face**, my dependence on my crutch, and maybe my appearance”*



Discussion

- Limited attention to sexuality
- Sexuality is still taboo – unlikely to be raised by anyone
- Sexuality is more than sex
- It IS uncomfortable, but survivors and their partners need help & support
- Huge significance for QoL





The lived experience (patient interview)

“to have had it (aspects of sexuality) just woven into the conversation along the way would have been nice”

“Not now doesn’t mean not ever”

→ raise it early and revisit it over time

“the greatest insult we can give a patient is shaming them... and that’s exactly what NOT asking does”



The P*Li*S*si*T Model (Annon, 1976)

- P** permission
- Li** limited information
- Ss** specific suggestions
- iT** intensive therapy

Who talks about sexuality??

EVERYONE can do P & Li

http://projects.hsl.wisc.edu/SERVICE/modules/3/M3_CT_The_PLISSIT_Model.pdf





How do I actually do it...?





Initiating a discussion about sexuality

- Setting & confidentiality
- Legitimation
- Empowerment
- Universalization
- Questioning

- WHEN?
 - ADL Ax, grooming, home visit with patient, first day leave...
 - ***“Have it early and have it often”***



***“the greatest insult we can give a patient is shaming them...
and that’s exactly what NOT asking does”***

(Stroke Survivor)





Initiating the discussion. 1: **P**ermission

“many people when they have had a stroke, have questions to ask about how a stroke affects their sexuality and their relationships. This is a very important topic. If you have any questions, you can ask me”

“Some people say that a stroke has changed their intimate relationship with their partner. Would you say your stroke has affected your relationship?”

“Some people feel that they are no long attractive following a stroke. Is that something that concerns you?”

“some people worry that if they have sex, they will have another stroke. Is this something that you are concerned about?”



Initiating the discussion. 1: **P**ermission

“Some people say that having a stroke has changed their confidence to start a new relationship. Would you say the stroke has affected your confidence in that way?”

“I see that you have weakness in your left arm. Are you still able to hug and be intimate with your partner as you want? Are you worried about this?”

“some people feel that because of changes in their speech, that they can't have intimate conversations with their partner. Is this something that you've experienced or would like to talk about?”

“some people say that having assistance with toileting changes the way they see themselves as a wife. Is that your experience?”



Initiating the discussion. 1: **P**ermission

“Some people say they no longer feel confident to kiss their partner because of drooling. Is this something that you are worried about?”

“Some people on a modified diet say this changes social outings as a couple. Are you worried this may affect your relationship and social life?”

“many people are concerned about how having a catheter might affect being intimate with their partner. Is this something that concerns you?”

“some people are concerned about body changes after a stroke and how this might impact on them being intimate with someone. Is this something that you want to talk about?”



Patients with communication difficulties

- Use your speech pathologist!
- Info in:
 - written prompts (size 14-18 Arial)
 - pen & paper, phone/tablet
- Info out:
 - pen & paper
 - simple cards - yes/no/ something else, & a picture or numerical rating scale of importance



The PLiSsiT Model (Annon, 1976)

- P** permission
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Who talks about sexuality??

EVERYONE can do P & Li

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2. Limited Information

- Providing written information
- Starting point for a conversation (“*do it early and do it often*”)
- Don’t forget to follow up!

All team members should be providing Limited Information!



Other resources

“Many people have questions about relationships & sexuality after their stroke. Here is some information that other people have found helpful. Let me know if you have any questions about this”

(**PLi** - **P**ermission & **L**imited information)



What you need to know

- Stroke can change how your body feels, works and how you feel about yourself. It can also affect your relationship with your partner.
- Studies have not shown that sexual activity can trigger a stroke.
- You may need to adapt to any physical changes, address any emotional changes, and talk to your partner or health professional.

How stroke can affect sex

Stroke can change how your body feels, works and how you feel about yourself. It can also change your relationships. Sex after a stroke may be affected by:

Fear of another stroke. Studies have not shown that sexual activity can trigger a stroke. If you are concerned, talk to your doctor.

Physical changes. Sexual activities can be impacted by physical changes including muscle weakness, stiffness, tightness, pain, altered sensation, mobility, fatigue and incontinence.

Emotion and mood changes. A stroke may change how you feel about yourself and your sexuality. It's common to feel a range of difficult emotions after a stroke:

anger, irritability and sadness. Depression and anxiety are also common after stroke. Emotional changes can impact your interest in sex.

Relationship issues. Changes in roles after a stroke can impact your sexual relationship, especially if one of you has taken on new responsibilities. You might be worried about how your partner will feel about you sexually. Your partner may be concerned that sex could cause you worry or pain.

Sexual dysfunction. Stroke is not usually a cause of sexual dysfunction. If you experience problems with getting or maintaining an erection, vaginal lubrication or reaching orgasm, it may be due to another condition such as cardiovascular disease or diabetes. It could also be a side effect of medications such as those for managing high blood pressure, depression or sleep problems.

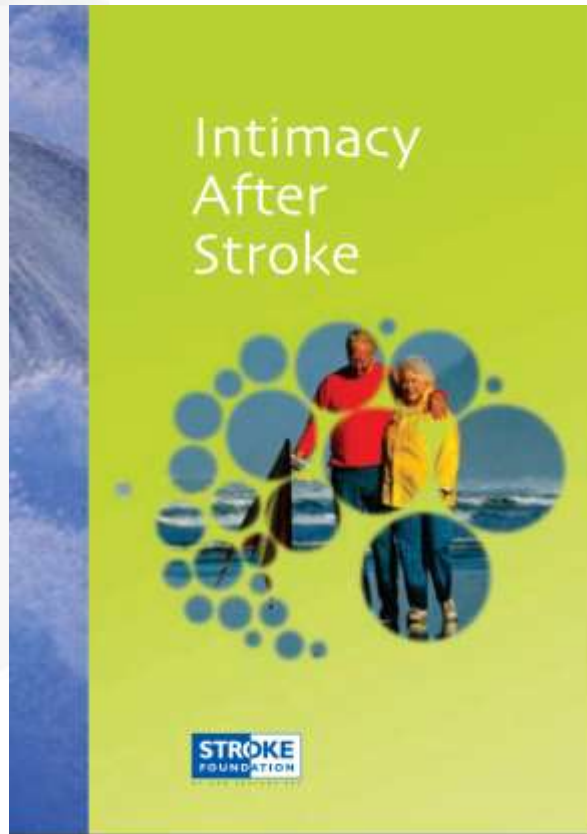
Things that can help

For some stroke survivors getting back to sex early on is important. Others only start to think about sex further along in their stroke recovery. Interest in sex can change throughout the recovery process.

Being in hospital can make you feel much less connected to your partner. If you are in



Other resources



Index

- 2 Introduction
- 3 Sexuality and body image
- 4 Attitudes and barriers
Fears about resuming sex, Fear about partner rejection, Fear of failure to perform, Medications
- 6 Getting started
Timing, Hygiene, Catheters, Paralysis
- 11 Adapting to change in your life
Sensory and perceptual changes, Communication, Cognitive change, Role changes, Birth control, Other ways to make love, Self-stimulation, Oral sex, Vibrators
- 14 Summary
- 15 Questionnaire on sexual functioning following a stroke



Other resources

<https://www.strokingengine.ca/wp-content/uploads/2015/02/Sexuality-Patient-Family-InformationJan2011.pdf>

SEXUALITY

Information for Patients and Families

Since my stroke I have difficulties with sexual performance. Is this normal?

Yes. Studies estimate that 65-75% of people who have had a stroke do experience a decrease in sexual activity. Problems with sexual performance can occur for a number of different reasons.

After a stroke, both men and women experience various physical impairments, including:

- Problems with ejaculation
- Problems with orgasm
- Decreased coitus (penetration)
- Erectile difficulties (problems having an erection)
- Decrease in frequency and/or duration of foreplay
- Decrease or absence of vaginal lubrication
- Urinary incontinence (inability to hold in urine)
- Difficulty expressing emotion due to speech impairment
- Increased fatigue
- Difficulty finding comfortable positions for sexual activity due to physical limitations

People also experience psychological problems, which may include:

- Insecurity (feeling less attractive)
- Fear of partner rejection
- Lack of interest in sex
- Lack of satisfaction
- Decreased libido (desire)





Other resources

23%
off

H E
ULTIMATE
GUIDE TO
SEX AND
DISABILITY

For all of us who live with disabilities,
chronic pain & illness

by Miriam Kaufman, M.D., Cory Silverberg, and Fran Odette

Ultimate Guide To Sex And Disability : For All of Us Who Live With Disabilities, Chronic Pain and Illness

★★★★☆ 4.16 (177 ratings by Goodreads)

Paperback | [English](#)

By (author) [Miriam Kaufman](#) , By (author) [Fran Odette](#) , By (author) [Cory Silverberg](#)

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The Ultimate Guide to Sex and Disability is the first complete sex guide for people who live with disabilities, pain, illness, or chronic conditions. Useful for absolutely everyone, regardless of age, gender, or sexual orientation, the book addresses a wide range of disabilities from chronic fatigue, back pain, and asthma to spinal cord injury, hearing and visual impairment, multiple sclerosis, and more. Expertly written by a medical doctor, a sex educator, and a disability activist, The Ultimate Guide provides readers with encouragement, support, and all the information they need to create a sex life that works for them. The authors cover all aspects of sex and disability, including building a positive sexual self-image; positions to minimize stress and maximize pleasure; dealing with fatigue or pain during sex; finding partners and talking with partners about sex and disability; adapting sex toys; and more."



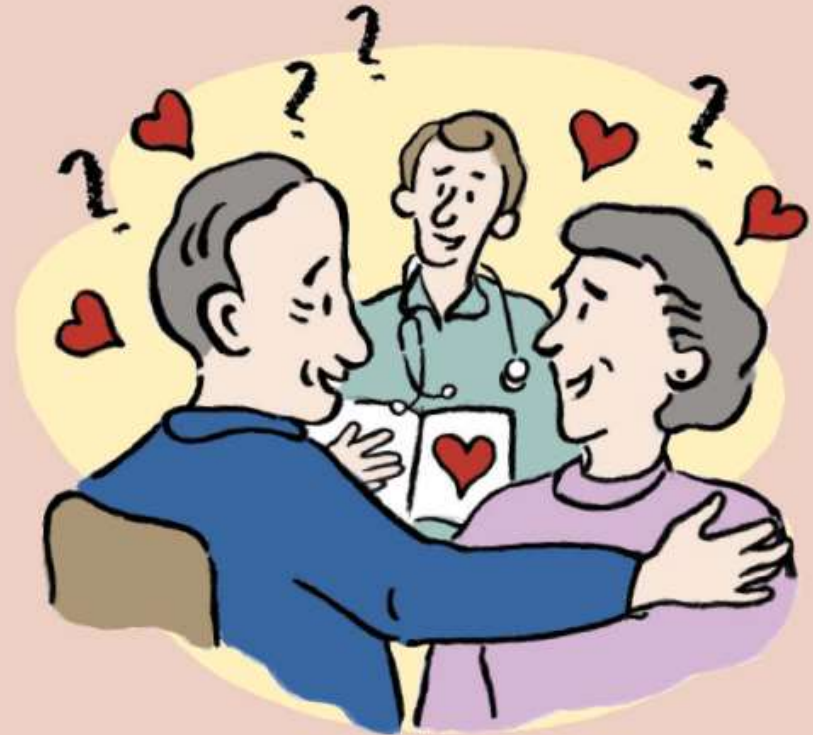
Specific Suggestions

(speech pathology)

Teach patients & significant others alternate ways of expressing emotion & affection early on
(*"I love you"*)

www.participics.ca

INTIMACY AND RELATIONSHIPS: TALKING TO YOUR DOCTOR



An interactive booklet for people and their medical practitioners



Intensive therapy (iT)

Get to know what is available in your area

What about country patients?



Summary

- Sexuality is more than sex – think broadly
- Stroke survivors need **all** health professionals to break the silence around sexuality
- PLiSSiT model is a useful framework to initiate discussions
- Practice increases confidence and comfort!
- If all health professionals consistently address the Permission and Limited Information stages of the PLiSSiT model we will have improved outcomes for stroke survivors and their partners



Acknowledgements

Sandra Lever, Annie McCluskey,
Emma Power & Margaret McGrath

*(the Sydney Sexuality
Research Group)*

