

INTIMACY AND SEXUALITY POST STROKE

Why it Matters

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DISCLOSURES

CARF Surveyor
UDS Consultant

OBJECTIVES

List at least three impairments post stroke that can adversely affect intimacy and sexuality.

Describe various ways successful return to intimacy and meaningful sexuality can contribute to maximizing quality of life post stroke for survivors and partners.

Discuss how a stroke rehabilitation center of excellence can best integrate programmatically issues related to sexuality into their stroke rehabilitation continuum of care.

Rehabilitation of people with disabilities is a process aimed at enabling them to search and maintain their optimal physical, sensory, intellectual psychological and social functional levels.

World Health Organization

The goals of rehabilitation are to help survivors become as independent as possible and to attain the best possible quality of life

US Department of Health and
Human Services

Quality of life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

World Health Organization

Quality of Life

The overall enjoyment of life

This includes an individual's sense of well being and ability to carry out activities of daily living



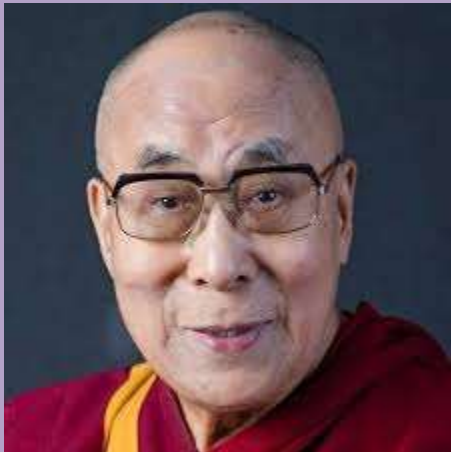
The job of any doctor is to support quality of life, meaning two things...as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world.



Juergen Bludau, MD

The purpose of our life is happiness

If you approach others with
compassion it creates a feeling of
affinity, a kind of connectiveness



The Art of Happiness

Dalai Lama

Howard Cutler, MD

Intimacy is the experience of
connectivity.

“The Art of Intimacy”
Thomas Malone
Patrick Malone

Latin intima – inner or innermost

The desire for intimacy is the desire to share one's innermost self with others.



Dr. Dan McAdams

Intimate attachments to other human beings are the hub around which a person's life resolves. From these intimate attachments a person draws his strength and enjoyment of life.



John Bowlby
British Psychoanalyst

Well being is all about relationships

Quality of life is all about relationships

Dr. Dan Gottlieb

Humankind's most basic fear is the threat of being separated from other humans and the experience of separateness is the source of all anxiety in human life.



Erich Fromm

Human sexuality is the way people experience and express themselves sexually. This involves biological, erotic, physical, emotional, social or spiritual feelings and behavior.

Sexuality is about who you're attracted to sexually and romantically.

Sexuality is shaped by many things including:

- Values and beliefs

- Attitudes

- Experiences

- Physical attributes

- Sexual characteristics

- Societal expectations

Stroke is the fifth leading cause of death and leading cause of disability worldwide.

Rodrigues et.al

International Archives of Medicine

2016

Most stroke survivors identify sexuality as an important issue in their post stroke rehabilitation.

Individuals with strokes are not satisfied with how the rehabilitation community addresses sexual dysfunction.

Rodrigues, et.al
2016

Patient Counseling Preferences

71% identified sexuality as moderate to very important

47% indicated sexual function declined post stroke

81% reported receiving insufficient information

26% wanted counseling prior to discharge

71% wanted counseling within one year

Stein, et.al

Disabil Rehabil 2013

Common myths regarding sexuality

People with disabilities are less sexual than persons without

Sex means sexual intercourse

Talking about sex is not natural, proper or necessary

Sex is for younger people

Men should initiate sexual activity

Sex should be spontaneous

A firm penis is a requirement for satisfying sex

Quality sex ends with an orgasm

Milton Klein, DO

Medscape, October 2018

Pertinent Post Stroke Impairments

Paresis

Sensory loss

Visual loss

Contractures

Pain

Cognitive deficits

Communication deficits

Incontinence

Depression/anxiety

Fatigue

Erectile dysfunction

Lubrication issues

Orgasmic problems

Location of stroke matters

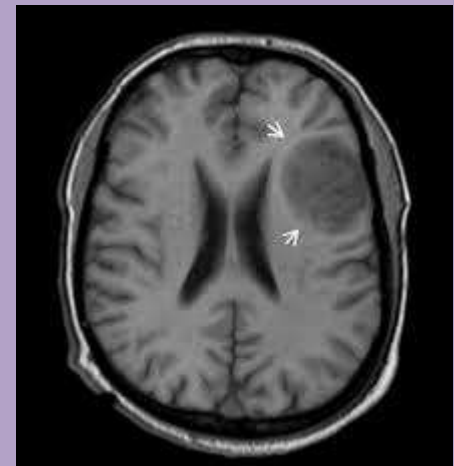
frontal lobe – disinhibition

temporal lobe – libido, arousal, pragmatics

R brain – attention, memory,
executive function

bilateral temporal – hypersexual

L brain - language



Medication Sexual Side Effects

Decreased libido, sexual desire

Erectile dysfunction

Difficulty achieving orgasm

Diuretics

Beta Blockers

Alpha blocker

Opioids

Antiepileptics

SSRI/SNRI

Tricyclics

Anxiolytics

Alcohol/Drugs

Female issues

Pregnancy/birth control

MenopausE/estrogen

Avoid estrogen > 10 years post menopause



Aging

Changes over time

Psychosocial/economic stress

Anxiety

Isolation



Body image concerns due to hemiplegia, language issues, facial droop, role change.

Survivors feel unattractive and unappealing

Insecurity, Fear, Doubt

A common cause of concern for survivors and caregivers is fear of causing another stroke

Making love takes about as much energy as walking up 1-2 flights of stairs

Role Changes

Caregiver → lover

Prior sexual roles

Provider/homemaker changes

Effects on self esteem

Role Changes

Masculinity linked to physical function

Provision of protection and security

Femininity linked to bodily aesthetics,
maternal role

LGBQT

Struggle to communicate

Not wanting to cause stress

Survivor is not capable or interested

Fear of rejection

Loneliness/isolation – lost partner

Two major themes were central to the experience after stroke

Sexuality is silenced

Sexuality although muted and sometimes changed is not forgotten

McGrath, et.al

For many, this means sexuality is lost, potentially leading to increased incidence of anxiety, depression and poor quality of life outcomes

Giaquinto, et.al

Increased risk of stroke with depression, anxiety and stress

Increased inflammatory factors

You need to understand your past, cultural and family issues. Some cultures are free; some are closed. Some families educate. Some cultures have a strong male head; others female. Some religions don't support masturbation or birth control.

Spectatoring

Masters and Johnson

Communication and openness is the secret to good sex. If you are unable to communicate and be honest with yourself about your fears and beliefs, it is hard to share with a partner. Conversely if you have good internal communication but are unable to share with your partner. Then having a good sexual relationship becomes difficult.



Sexual Sustainability
Marcalee Alexander, MD

I would rather know what sort of person
has a disease than what sort of disease a
person has



Hippocrates

The outcome of tuberculosis had more to
do with what went on in the patient's mind
than what went on in his lungs

Sir William Osler

PLISSIT Model

Permission

Limited information

Specific suggestions

Intensive therapy

Communication (verbal/nonverbal)

Patience

Perseverance

Medication review

Lubrication

BC/protection

Masturbation

Vibrators/toys

Positioning

Mindfulness

Counseling

Peers

Timing

Hygiene

Bowel/bladder

Environment/mood

Planning

Communication

Pre

During

Post

Start slow but start

Closeness

Cuddle

Humor

Say what feels good

Kiss, touch, hug

It's not just about vaginal penetration

2013 AHA Consensus Document

All stroke survivors and their partners should be asked about intimacy and sexual function at the time of the stroke and at regular intervals during follow-up.

Sexual activity is reasonable for patients after stroke.

To reduce the psychological sequelae associated with stroke, sexual counseling can be useful for most patients and their partners.

Kautz, VanHorn

International Journal PM&R 2014

Rehabilitation Center of Excellence and Significance

Comprehensive

Connected

Continuum

Coordination

Communication

Community

Educate

Evaluate

PCP

Neurology

OB/Gyn

PM&R

OP staff

Urology

Administration

Acute Rehab

SNF

Assisted Living

Continuum

Timing of intervention

Follow up

Telerehab

Active evaluation/intervention

Roles

Please remember that information doesn't change anyone. Inspiration does. Find your reason to live. Be inspired by it and undergo revelation and transformation. I have found only one bit of information that could help change you: It is that you are mortal and will die some day. Therefore, don't do things to not die but do things to enhance the quality of your life and you may be surprised by how long you do live. Accept that you will die and made decisions about how you want to spend the limited amount of time you have.

Love, Medicine and Miracles
Bernie Siegel, MD

We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it's larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.

Being Mortal

Atul Gawande

Behind mountains are more mountains



Haitian proverb

The answer lies not in return but in transformation.

We can only go forward to what we can be.

Rabbi David Wolpe
Making Loss Matter

“My experience throughout my recovery is that life unfolds in ways we can’t predict. If you encounter a difficult challenge in your own life. I hope you’ll remember that this challenge doesn’t have to define or limit you. You hold an amazing power to influence the course of your own life. How you respond to the challenges of your life can become your opportunity to discover just how much you have to give to yourself, this world and the people in it.”

Alison Bonds Shapiro
Healing into Possibility

Thank you