

Webinar Series



Relationships and Intimacy

Tuesday, August 11, 2020

Presented by:

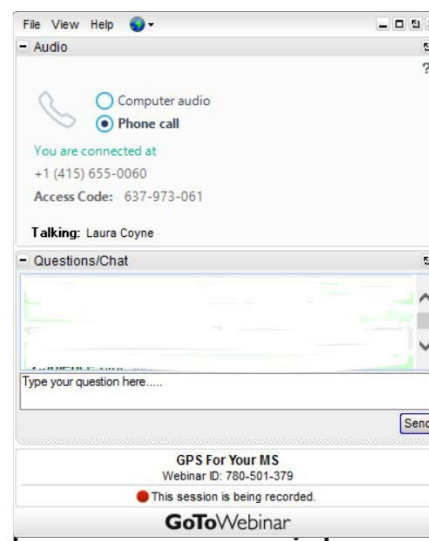


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Learning Objectives

- Understand the ways in which MS symptoms can impact roles and relationships.
- Learn strategies for discussing and problem-solving changes in intimacy.
- Learn strategies for maintaining a balanced and satisfying partnership.

What to Expect from this Presentation

- There are many factors that can impact sexual functioning. Think of this presentation as a brief overview of the potential contributors. Some may fit you, some may not.
- For anything that might apply to you, write it down. Then explore possible interventions until you discover what makes things better.
 - There may be more than 1 contributor
 - Barriers may change over time

What Does Intimacy Mean?

- **Definition:** Warmth, Connection, Closeness, & Trust
- Deeply knowing another person and feeling deeply known
- It can, but does not always, involve:
 - Communication
 - Spending time together
 - Hand holding, cuddling
 - Sexual touching
 - Intercourse

Polling Question 1

How would you identify

- a) Male under age 40
- b) Male over age 40
- c) Female under age 40
- d) Female over age 40

Polling Question 2

How would you identify

- a) Support partner
- b) Person with MS, no assistive device
- c) Person with MS, use mobility device (e.g., cane, walker, wheelchair)

Intimacy and Sex is an Important Part of Our Overall Health

- Improves immunity
- Improves sleep
- Improves heart health
- Reduces pain
- Reduces risk of prostate cancer
- Reduces stress
- Increases brain power
- Increases self esteem
- Increases life span

MS Can Interfere with Sex

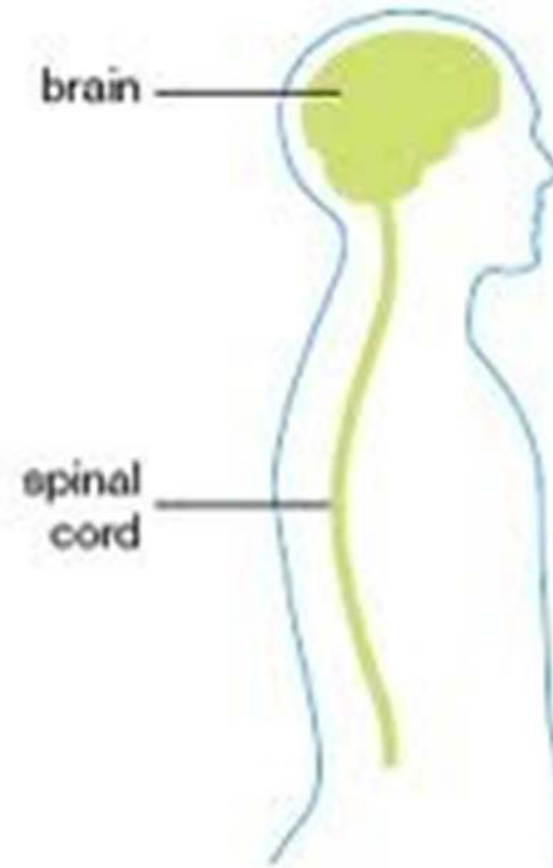
- 80% of people with MS experience a sexual problem
- 35% - 40% of general population report at least occasional problems with sexual functioning
- It is your right to ask questions as a regular part of your health care!



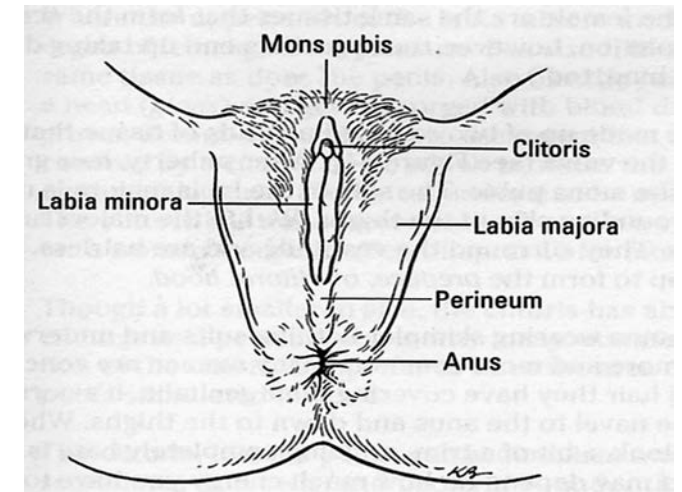
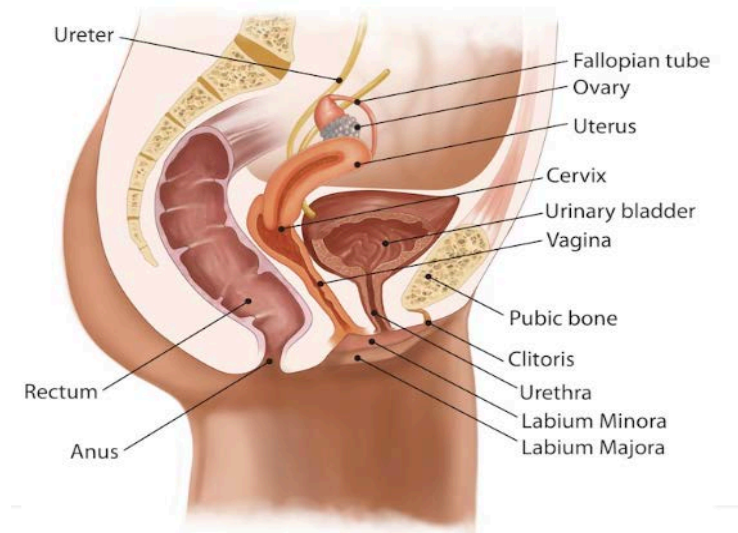
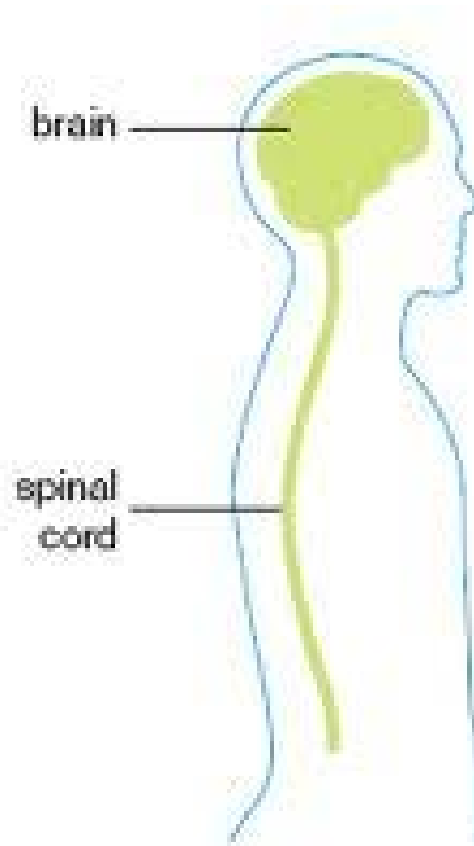
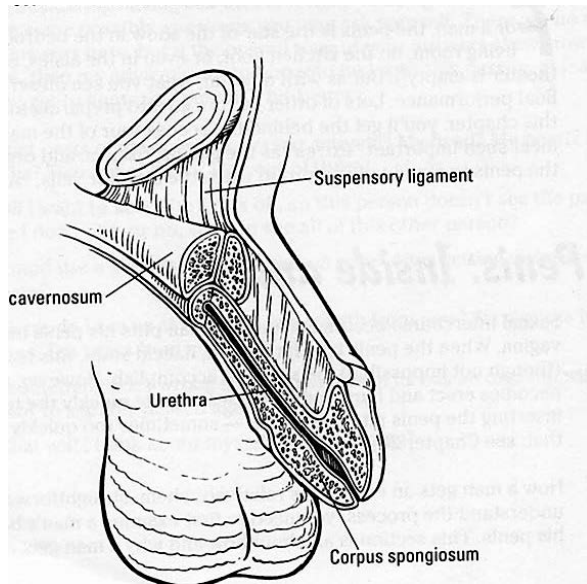
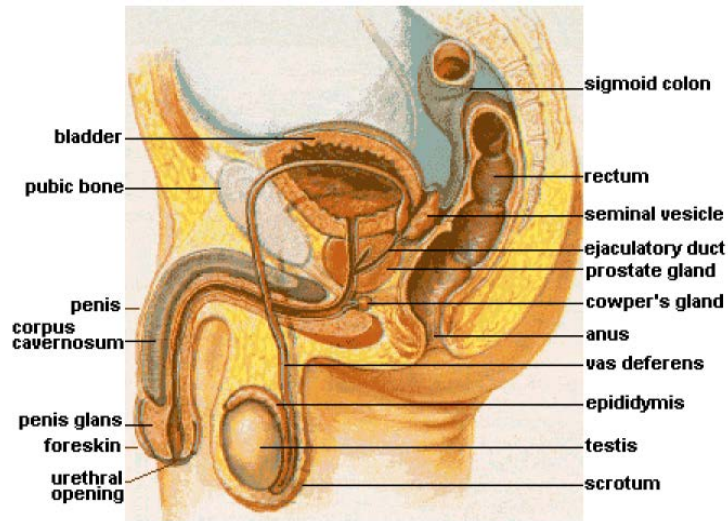
A Little Anatomy and Physiology

Central Nervous System (CNS)

- Sexual arousal begins in CNS; the brain sends messages to sexual organs along the nerve pathway in the spinal cord
- MS lesions in spinal cord or brain can change nerve pathways and create disconnect between the brain and physical sexual functioning
- Can directly or indirectly cause sexual dysfunction



Sexual Anatomy



Polling Question 3

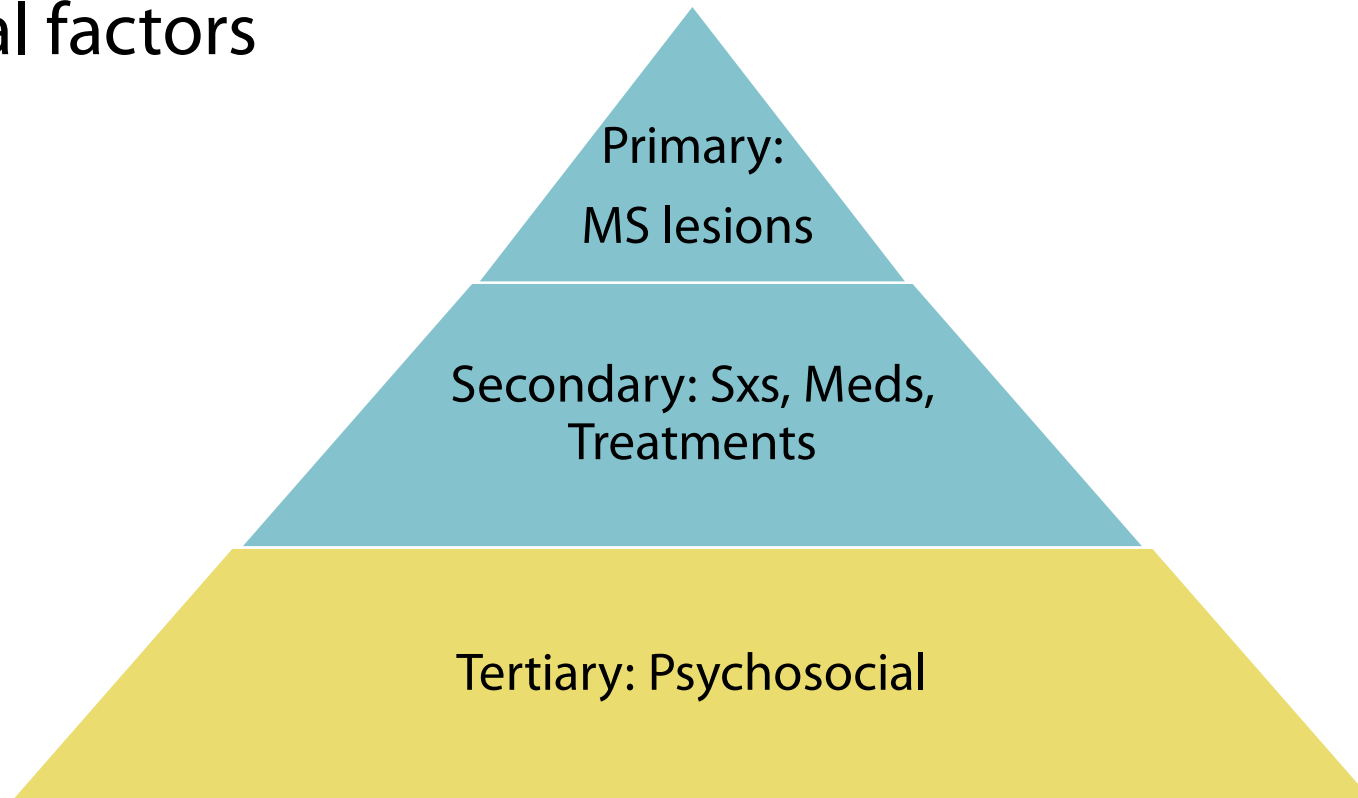
How frequently in the past 12 months have you experienced intimacy challenges?

- a) Never
- b) A little (less than 25%)
- c) Occasionally (26-50%)
- d) Frequently (51-75%)
- e) Consistently (76-700%)

It All Starts in the Head

Tertiary Symptoms:

Sexual issues caused by emotional symptoms, role changes, or psychosocial factors



Communication is ESSENTIAL with... Your Healthcare Team

Why Hasn't My Medical Team Asked Me About Sex?

- Limited time with patients (44%)
- “Outside of my role” (15.3%)
- Patient discomfort (12.5%)
- Lack of professional training or comfort (6.9%)
- Other priorities (5.6%)
- Limited medical coverage so they cannot afford treatment (2.8%)
- Too intrusive for patients (2.8%)
- Patients typically rely on the clinician to discuss issues in sexual functioning and many are grateful when the topic is addressed. (Foley, 2006).

Polling Question 4

Do you feel comfortable discussing sexual issues with...

- a) My partner, but not healthcare team
- b) My healthcare team, but not my partner
- c) Neither my partner, nor my healthcare team
- d) Both!

Healthcare Team: Who Can I Talk To?

- PCP
- Nurse Practitioner or PA
- MS Neurologist
- Nurse in office/Case Manager
- Counselor/Psychologist
- Urologist
- Therapist: PT, OT, or Physiatrist – Consider a pelvic floor therapist

Healthcare Team: What to Share

- Length of time you've experienced issues
- If you have tried to address issues already, how?
 - What worked, what didn't?
- How it is impacting (e.g., pain, loss of libido, dryness, etc.)
- Age and sex of your partner(s)
- Is partner also having issues?

Wait a Minute! Let's Investigate!



Medical Conditions

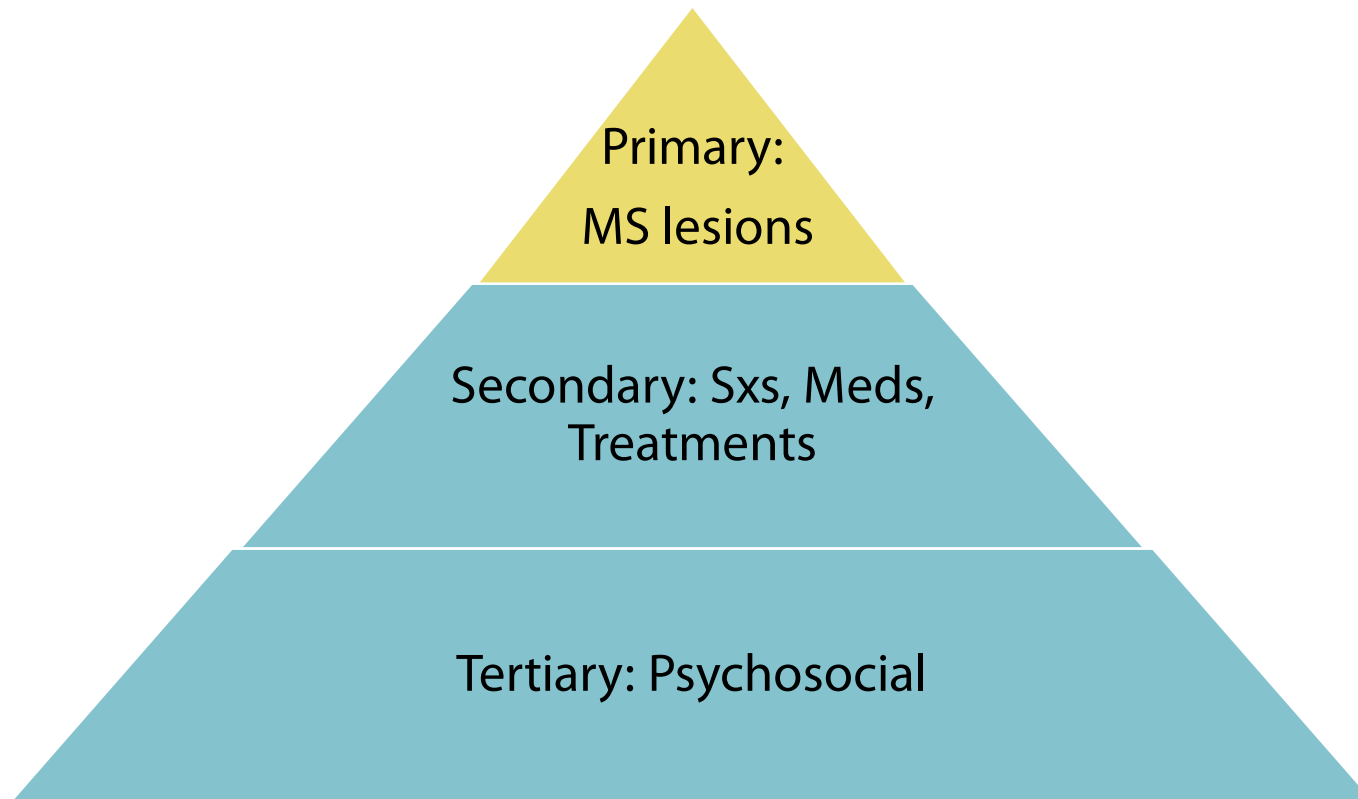
- Vascular problems
 - Diabetes
 - High blood pressure
 - High cholesterol
- Hormonal disorders
- Tobacco use
- Depression
- Obesity
- Prostate enlargement (ED)
- Changes in pelvic structures (fibroids, endometriosis.....)

Medications and Other Substances

- Blood pressure meds (may cause erectile dysfunction)
- Antidepressants (desire, ED, impair orgasm)
- Opioids (over time decrease testosterone and ED)
- Antihistamines/Decongestants (ED and ejaculation problems)
- ETOH (diminishes performance and delays orgasms and ejaculation)
- Antiepileptics (Gabapentin and topiramate orgasmic dysfunction)
- Anti reflux drugs

Primary Symptoms

Sexual issues caused by a lesion in the brain or spinal cord



Primary Sexual Effects MS Can Cause

- These symptoms can occur as a direct result of myelin breakdown in the spinal cord or brain:
 - Decreased sex drive
 - Altered genital sensations (numbness, pain, increased sensitivity)
 - Difficulty or inability to maintain erection
 - Decreased vaginal lubrication
 - Decreased vaginal muscle tone
 - Difficulty to ejaculate
 - Problems having an orgasm

Treatment – Loss of Libido / Desire

“Having my partner massage me gently beforehand helps me get in the mood more, either using a scented or plain oil.”

Can be a direct result of lesions or due to anxiety, fatigue, loss of self-esteem, or a medication side effect

- Make time for foreplay
- Relax: listen to relaxing music, a mindfulness app, do some deep breathing, communicate
- Try a body mapping exercise
 - (for more details see Sex & MS: A Guide for Women, link at the end of this presentation)

♀ Treatment Strategies – Lack of Sensation

“In order to reach orgasm I have to use a vibrator. It was actually a partner who suggested it and I was very embarrassed at first, but it’s brought an added dimension and creativity to sex! I would urge anyone who is having difficulty in reaching orgasm to invest in a vibrator!”

- Alterations in orgasms
 - Vibrators / clitoral vacuum device
 - Estrogen replacement
 - Explore alternative sexual touches
 - Oral sex
 - Different sexual positions
- Communication



♀ Treatment Strategies – Let's Talk Lube

Decreased lubrication

- Incorporate liberal application of water-soluble lubricants prior to and during sexual activity (e.g., Good Clean Love, Slippery Stuff, and Sliquid Organic)
- Lubricants that contain menthol or other vasoactive agents can sometimes improve sensation.
- Lubes with coconut oil and aloe vera are good for patients with genital pain, but can't be used with condoms
- Silicone-based lubes are good for someone with pelvic pain that is using a condom

♂ Treatment Strategies – Erectile Dysfunction

- **Phosphodiesterase inhibitors:**

- Sildenafil (Viagra®) PO 30-60 min before sex
 - Improve 89% of men vs. 24% placebo
 - SEs (6-18%) : headache, flushing, dyspepsia
 - Contraindicated: in patients taking nitrates or had a MI / stroke within past 6 months

- Vardenafil (Levitra®)

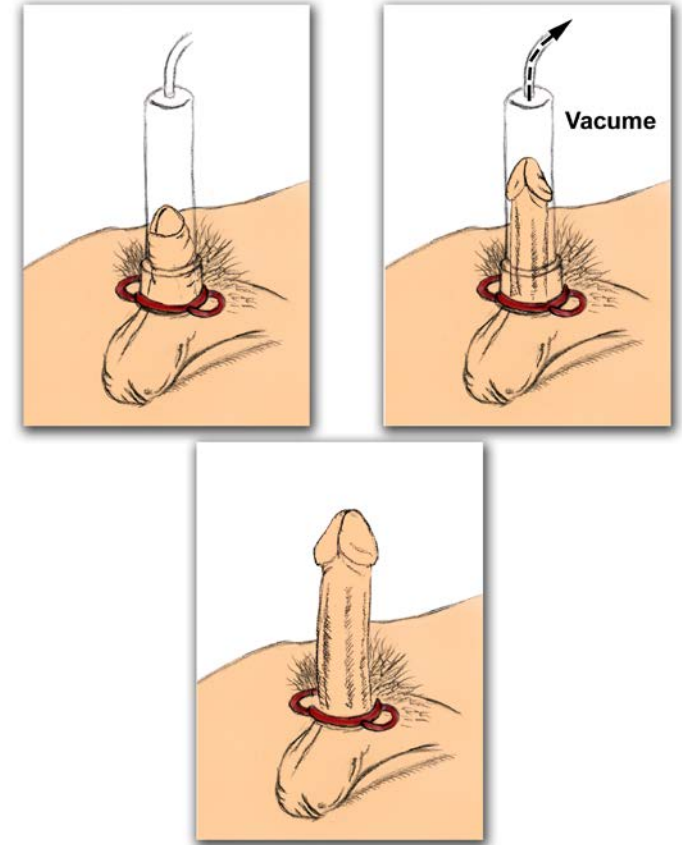
- Tadalafil (Cialis®)



♂ Treatment Strategies – Men

- **Vacuum erection device**

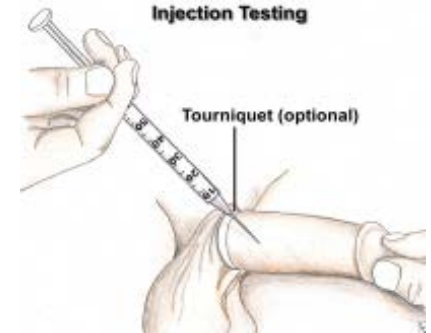
- Negative pressure produced by either manual pumping or battery operation



♂ Treatment Strategies - Men

- **Prostaglandin E1 (alprostadil):**

- Injectable prostaglandin (alprostadil, Caverject, Edex) into penis
 - 30 minutes before intercourse (95%)
 - SEs: dysethesias, priapism, seizures, intracorporeal fibrosis



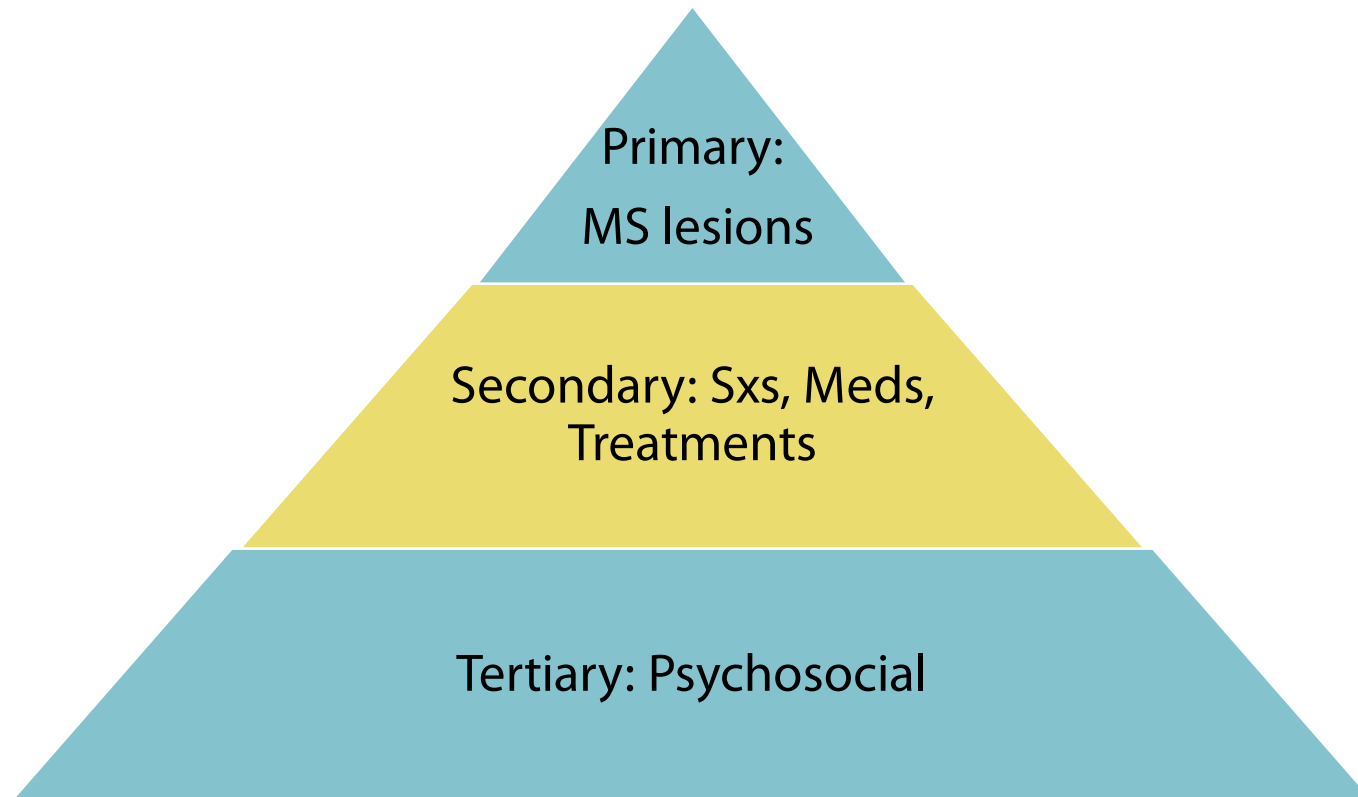
- **Penile prosthesis:**

- Semi-rigid
- Malleable



Secondary Symptoms

Sexual issues caused by MS symptoms, medications, or treatments



Secondary Sexual Effects

- These symptoms can arise as a consequence of MS, physical changes or treatments:
 - Fatigue can suppress sexual desire
 - Spasticity can interfere with sexual positioning or cause pain
 - Bladder or bowel problems are closely related with sexual dysfunction because the nerve pathways are nearby or shared.
 - Sensory changes can make physical contact uncomfortable.
 - Pain

Treatment – Bladder Issues

- Bladder dysfunction
 - Urinary leakage
 - Bathroom or cath before sexual activities
 - Avoid fluid intake several hours prior to sex
 - Pad on bed
 - Males condom
 - Kegel exercises
 - Urinary tract infection
 - Bathroom after sexual activity
 - Catheters? Yes you can!

Treatment – Bowel Issues

Bowel dysfunction

- Empty bowels before sex
- To help empty bowels: micro enema, transanal irrigation system (Peristeen, Qufora)
- Temporary anal plug



Micro enema



Anal plug



Peristeen

Treatment - Spasticity

“I find lying on my back clutching a knee with each hand towards my shoulders works. My knees have to be bent right up to break spasticity. This position also means I can have lazy sex when I’m knackered!”

Spasticity

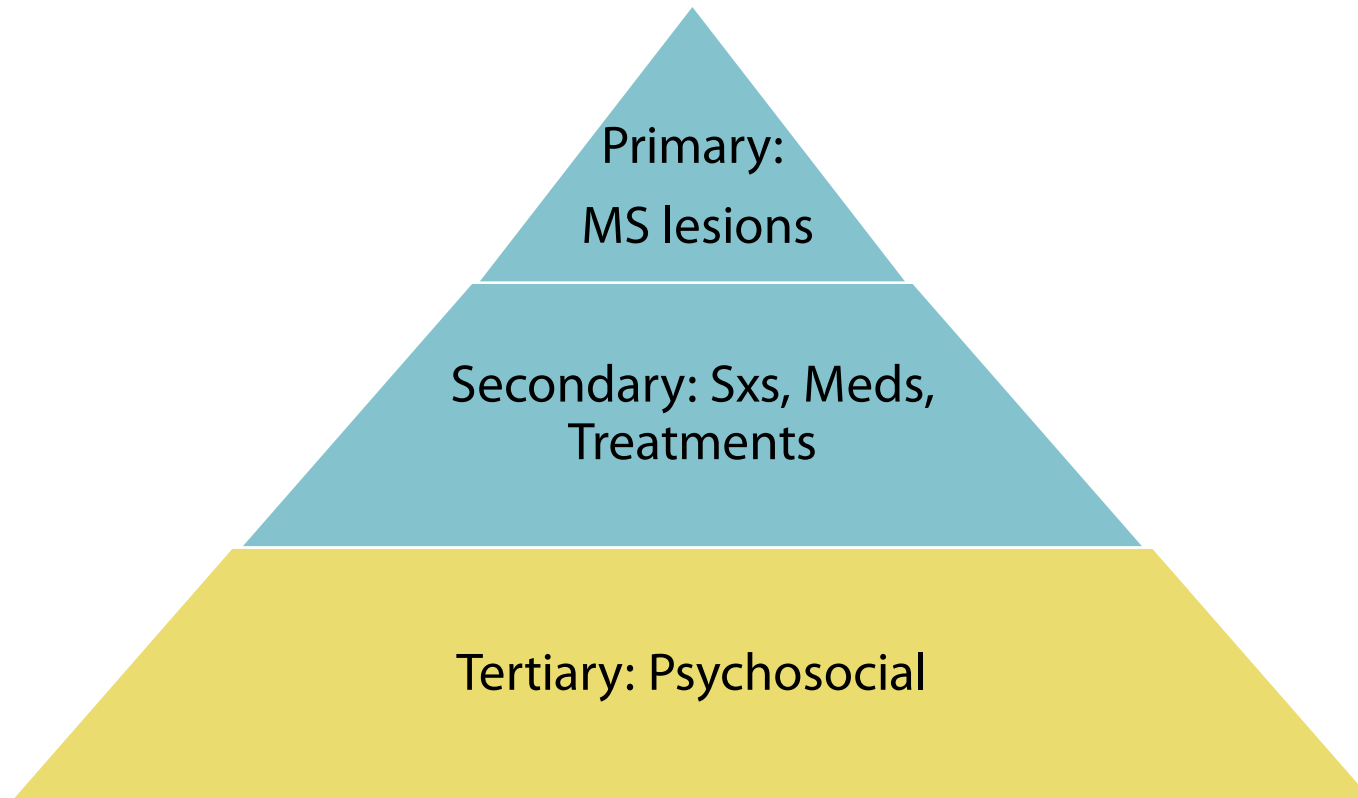
- Stretching
- Anti-spasticity medications
- Positioning

Treatment - Fatigue

- Timing – when do you have the most energy?
- Anti-fatigue medications
- Change positions, use position that take less energy
- ‘Stop, start’ technique – taking a break when you start to tire, then starting again
- Quickie
- Stay cool

Tertiary Symptoms Continued

Sexual issues caused by emotional symptoms, role changes, or psychosocial factors



Tertiary Sexual Effects

- These symptoms result from psychological or social issues that interfere with sexual feelings and/or response:
 - Depression
 - Performance anxiety
 - Changes in self-image or body image

Communication is ESSENTIAL with... Your Partner(s)

Communication, Communication, Communication

“It was worth the embarrassment of telling my partner what I really enjoy. Now he really knows what turns me on!”

- Only 9% of couples are comfortable talking about sex
- Having sex and talking about sex often involves vulnerability
- Reduced connection, intimacy, and feeling safe leads to pulling back

Communication: Same-Sex Couples

In a 12-year study of gay and lesbian couples Drs. Gottman and Levenson found:

- Same sex unions were comparable in satisfaction and quality
- “Gay men [and lesbians] tended to be much more direct. In terms of conflict management, there was much less physiological flooding. There was more humor during their conflicts. They were often good friends, and they could talk much more directly about sex and therefore had more contented sexual relationships because they really understood each others’ needs..”

Couples Who Have Great Sex Do the Following:

- They say “I love you” every day and mean it
- They kiss one another passionately for no reason
- They give surprise romantic gifts
- They know what turns their partners on and off erotically (**COMMUNICATE**)
- They are physically affectionate, even in public
- They keep playing and having fun together
- They cuddle
- They make sex a priority, not the last item of a long to-do list
- They stay good friends
- They can talk comfortably about their sex life
- They have weekly dates
- They take romantic vacations
- They are mindful about responding to their partner’s bid for attention

Couples Where Sex Satisfaction Declines:

1. Spend very little time together during a typical week
2. Become job-centered and/or child-centered
3. Talk mostly about their huge to-do lists
4. Seem to make everything else a priority other than their relationship
5. Drift apart and lead parallel lives
6. Are unintentional about turning toward one another

A Few Tips for Talking about Sex

- **Prime the conversation:** “I’d love to talk about how MS is impacting our sex life, and how we can make it better for both of us. Can we talk about it tonight after the kids go to bed?”
- **Give reassurance.** “I frequently feel attracted to you, but the kids really sap my energy. What if I told you each time I felt attracted to you?”
- **Describe your experience. Ask for your partner’s experience.** Listen, ask questions, and try to be non-defensive when listening.
- **Make suggestions, not complaints.**
 - “I really love it when you...”
 - “I was thinking if we used [vibrator/towel] it might help me feel more comfortable and into it despite my [numbness/bladder issues]

What About Dating?

“I wait until the second date before I tell. If I like someone enough to see them again, I reckon I should tell them. If I leave it longer it feels like the elephant in the room. Somehow that seems to make it a bigger deal than it is for me; MS is just a small part of my life.”

- There is no right or wrong time
- Do what feels right for you
- You can not predict a person’s reaction - you may be surprised by the number of positive responses
- You also can not prevent negative reactions

Tools

- **Quiz: Gottman Quality of Sex, Romance, and Passion**
<https://www.gottman.com/blog/quiz-what-is-the-state-of-your-sex-life/>
- **Where do I start with improving communication about sex?**
Free app: <https://www.gottman.com/couples/apps/>

Resources

- Sex & MS: A guide for women (MS Trust UK):
 - <https://support.mstrust.org.uk/file/WOMENS-SEX-WEB.pdf>
- Sex, Intimacy, and Relationships (MS Society UK):
 - https://mss-cdn.azureedge.net/-/media/82e22396d5bf49eea22e29ed27131eaf.pdf?sc_revision=3c65e1423f754b039e103fb8c56e5568
- #Shiftms Video:
 - <https://www.youtube.com/watch?v=0oV-o2h1IEE>

Resources, Continued

- Jeremy's Video:
 - <https://facingdisability.com/spinal-cord-injury-videos/social-life-and-sex/what-about-sex-and-dating/jeremy>
- Sex with a catheter:
 - <https://www.youtube.com/watch?v=SKnv1z90eew&feature=youtu.be>
- American Association of Sex Educators, Counselors and Therapists (AASECT):
 - aasect.org
- o.school:
 - <https://o.school>

Key Take-Aways

- Investigate
- Determine problem areas
- Talk
- Explore
- Learn
- Have a sense of humor
- Teach



Q & A





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Pain Management

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Cited Sources

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<https://www.gottman.com/blog/building-great-sex-life-not-rocket-science/>
- Sloan Center UCLA study of 30 dual-career heterosexual couples
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