Learning for Life: Managing MS-related Sexual Dysfunction
Presented by the National Office of the MS Society of Canada
Managing MS-related Sexual Dysfunction

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Managing MS-related Sexual Dysfunction

Our Mission
To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.
Managing MS-related Sexual Dysfunction

The Multiple Sclerosis gratefully acknowledges the support of Biogen Idec for an unrestricted educational grant which makes possible the Learning for Life: Managing MS-related Sexual Dysfunction.
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Learning for Life - Spring 2006
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Characteristics of healthy relationships

- Effective communication
  - Talking
  - Listening
  - Recognizing agreement
  - Acknowledging differences
- Respect
- Trust
- Shared goals/expectations
- Mutual concern
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How MS challenges relationships

MS changes the “rules.”

• “I don’t feel like myself any more.”
• “This isn’t the way it was supposed to be.”
• “This isn’t the person I married.”
• “Our partnership is changing.”
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More challenges to relationships

- The “uninvited guest” is ever-present.
- MS introduces additional unpredictability.
  - “What can we count on from each other?”
  - “What can we count on today, tomorrow, and in the future?”
- A chronic disease strains resources (time, $$, energy).
- MS interferes with communication
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Communication is...
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Barriers to communication

- Lack of information—”I don’t know how to talk about this.”
- Different coping/communication styles:
  - “I want to know everything about MS.”
  - “He/She doesn’t want to know from MS.”
  - “I’m a talker—he/she is the silent type.”
  - “I’m a planner—he/she wants to wait and see.”
- Secrecy—”No one can know about this.”
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More barriers to communication

- Feelings
  - Anxiety-”This is too scary to talk about.”
  - Denial-”There’s nothing to talk about.”
  - Protectiveness-”I don’t want to upset him/her.”
  - Guilt-”My [resentful] feelings aren’t nice.”
  - Embarrassment-”I can’t talk about __________.”

Silence is often misinterpreted as NOT CARING
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Communication takes practice

- At home
- In support groups
- At educational programs
- On the Internet
- With a family therapist if a jump start is needed
How MS affects sexual intimacy

Alteration in relationship patterns
Changes communication
Changes roles and responsibilities
Shakes up the partnership
Sexual dysfunction
Primary—direct effects of demyelination
Secondary--indirect effects of other MS symptoms/the medications used to treat them
Tertiary sexual dysfunction—feelings, attitudes, cultural messages
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Primary Sexual Dysfunction

- Women report:
  - Decreased interest/arousal
  - Decreased vaginal lubrication and engorgement
  - Decreased vaginal muscle tone
  - Sensory changes in vaginal area
  - Decreased intensity or frequency of orgasms
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Primary Sexual Dysfunction

- Men report:
  - Decreased or absent libido
  - Inability to achieve or maintain erections
  - Decreased or altered sensation
  - Decreased intensity or frequency of orgasms
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Secondary Sexual Dysfunction

• Fatigue
• Spasticity
• Bladder/bowel symptoms
• Tremor
• Cognitive changes
• Medications
  – Anticholinergics, antidepressants, antispasticity agents
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Tertiary Sexual Dysfunction

• “Disabled people aren’t sexually attractive.”
• “I can’t be both a caregiver and a lover.”
• “If I don’t like myself any more, how can I expect someone else to find me attractive?”
• “This isn’t the same person I married.”
• “He/she doesn’t find me attractive now that I’m a burden.”
• “With everything else that’s going on, sex is the last thing I care about right now.”
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Treatment for Primary Sexual Dysfunction in men

- Viagra®; Levitra®; Cialis®
- Injection therapy (alprostadil; papavarine)
- Penile prostheses
- Vacuum pump
- Body mapping exercises
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Treatment for Primary Sexual Dysfunction in women

- Water-soluble lubricants
- Body-mapping exercises
- Phenytoin, carbamazepine (parasthesias)
- Vibrator
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Treatment for Sexual Dysfunction

• Secondary
  – Symptom management
  – Medication management/scheduling
  – Making a “date” for sex

• Tertiary
  – Education
  – Counseling
  – Support
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Hints for Dating Relationships

- MS is part of life but not all of it.
- First dates don’t require show-and-tell.
- If worth pursuing, it’s worth telling.
- Tell when you would want to know.
- Half-truths lay a shaky foundation.
- Risk is easier up front.
- Some will be frightened off; others will not.
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Summary

• MS can impact intimacy and sexuality in a variety of ways
• MS can cause primary, secondary, and tertiary sexual dysfunction
• Patients need to raise the issue because their physicians may not
• Treatment needs to address both the physical and the emotional components
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Sara & Brian

• Living together 2 yrs; contemplating marriage and children. Both age 26.
• Brian: dx 3 yr; sx: fatigue; sporadic erectile dysfunction; takes disease-modifying drug; uses Viagra as needed.
• Brian: wants to forget about MS for awhile and go ahead with their plans.
• Sara: increasingly anxious and “turned off.”
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Carol & Judy

• Together for eight years
• Carol: age 32; dx 4 years ago; works p/t; sx-fatigue, depression, bladder problems, lack of libido; vaginal dryness; anorgasmia
• Judy: confused by invisible sx; a “doer” rather than a “talker;” thinks it’s her fault
• Sex is high on Judy’s list and low on Carol’s.
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Sonia

• Single, 28yo professional woman; dx 1 yr
• Sx: fatigue, sensory changes, bladder urgency, vaginal dryness, anorgasmia
• Takes an injectable medication
• Ended a long-term relationship at time of dx. Scared to date, but doesn’t want to be alone for the rest of her life.
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Jason & Leslie

- Married 25 years; three teenage children
- Jason: dx. 12 yrs; sx: mobility impairment; cognitive impairment; sexual disinhibition (inappropriate language, fondling aides; grabbing Leslie in public)
- Leslie: embarrassed, hurt, angry, confused
- Children: scared; embarrassed; “grossed out”
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Question and Answer
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For more information on MS-related sexual dysfunction, or any other MS topic, please contact the National Information Resource Centre Program at 1-800-268-7582.