Welcome to... real talk real answers

living with ms in your 20s and 30s

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National Multiple Sclerosis Society
Multiple Sclerosis and Your Relationships

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Agenda

- Emotional response to the diagnosis
- Telling others
- Healthy relationships
  - Family
  - Friends
  - Dating
  - Intimacy and Sexuality
  - Family Planning & Pregnancy
- Living Well with multiple sclerosis
Response to MS

Each Person is Unique
Living with MS

- The uninvited guest vs. unexpected intrusion?
- Lifelong disease
- Unpredictable course
- Life gets more complicated!
- Where do we go from here?

Individuals are Unique

• Each person’s response is unique
  – Uncertainty and anxiety
  – Adaptation and adjustment
  – Grief
  – Re-emergence

• Solutions
  – Knowledge
  – Take control

Find a place for MS while keeping MS in its place!
Team Approach to MS Care

REACH OUT for support and help when needed!

Nurse/ARNP
Neurologist/Primary Care Physician
Vocational Rehabilitation
Physical Therapist
Social Worker/Counselor
Orthopedist
Psychiatrist
Physiatrist
NMSS/Resources
Psychologist/Neuropsychologist
Occupational Therapist
Speech and Language Pathologist
Urologist
Vocational Rehabilitation
Patient
Who, When and How to Tell!
Let’s Talk

• The “universal need”
• No absolutes: take the initiative
• Privacy is important
• Timing is crucial
• Set boundaries
• Tailor the information
• Keep the inner circle
Individuals are Unique

- Be fully educated about MS

- Communicate
  - Two-way traffic
  - Be clear and concise
  - Be honest and direct
  - Be attentive
  - Be positive

Healthy Relationships
Characteristics of a Healthy Relationship

• Communication: Talking is the main way we feel close to another person
• Trust
• Respect
• Mutual concern
• Tolerance
• Patience
Family balance

- All family members’ needs must be met
- Plan for the future, be strategic
- Re-negotiate relationships with parents

- Consider cultural issues
- Set boundaries
- Maintain independence

Kalb, R., Miller, D. (2004) In Multiple Sclerosis: The questions you have, the answers you need, 3rd Ed. Psychosocial Issues.
Family Support

- **Exchange of information: TALK**
  - Keep a sense of purpose

- **Talk about your concerns**
  - Provides reassurance
  - Reduces feelings of isolation
  - Encourages independence

- **Healthy relationships decrease stress**

Kalb, R., Miller, D. (2004) In *Multiple Sclerosis: The questions you have, the answers you need, 3rd Ed.*
Consider Counseling

• A safe place to talk

• Validation

• Help with communication skills

• An understanding of the impact of beliefs on emotion
Friends

- Maintain close relationships; don’t withdraw

- Engage in activities together

- Remember friends care and are concerned

- Be selective in how much you share
  - Be patient with their response
  - Be straightforward and concise

Dating

• Take time to get to know yourself
  — Remind yourself you are a person, not a “patient with MS”

• Engage in activities that produce more confidence
  — Seek methods for creating positive impressions
  — Practice stress reduction before dates

• See your old friends to meet new ones

• Consider Internet dating

• Discuss MS when you are comfortable
  — If it’s worth pursuing, it’s worth telling

Intimacy

• How is it defined?
  – Sex, love, caring, sensuality, touching, honesty, commitment, acceptance, conversation, body language

• Be comfortable with your own sexuality

• Work at sharing feelings

• Develop good sexual communication skills
  – Sexy Shoes: Think sexy

• Plan ahead for intimate moments

• Seek sexual counseling if needed

Talk About Sex

• Silence can be misunderstood as not caring
• Agree on when and where to talk about sex
• Use books, handouts and videos to initiate discussion
• Confide in your partner
  – Use positive language: “I would like”
• Rejection of sexual requests does not mean rejection of you as a person

Foley, F. (2001). In Multiple Sclerosis. 7(6). Rehabilitation of Sexual Dysfunction in MS.
Primary Sexual Dysfunction

- Occurs in up to 90% of men and 80% of women

- Men and women can experience difficulties
  - Decreased or absence libido
  - Altered genital sensations
  - Decreased frequency/intensity of orgasm
  - Erectile dysfunction
  - Decreased vaginal lubrication & clitoral engorgement

Foley, F. (2001). In Multiple Sclerosis. 7(6). Rehabilitation of Sexual Dysfunction in MS
Secondary Sexual Dysfunction

- Bladder or bowel dysfunction
- Fatigue
- Spasticity
- Tremor
- Pain
Interventions for Sexual Dysfunction

- Communication skills: TALK, avoid avoidance!
  - Speak with your healthcare professional
    - Complete medical evaluation
    - Treat underlying symptoms/secondary dysfunction

Interventions for Sexual Dysfunction

• **Non-pharmacologic strategies include**
  – Rediscovering and redefining variations in lovemaking
  – Mechanical devices
  – Re-positioning
  – Body mapping
  – Lifestyle changes

• **Counseling that targets intimacy and sexuality**

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Contraception

• Oral contraceptives appear not to affect
  – Risk for developing MS
  – Overall disease course

• Any method of contraception is appropriate; talk to your healthcare professional

Deciding to Have Children

- Discuss with partner: TALK!
- Personal choice
- Consider options
- Adjustments may be necessary in the long-term
Pregnancy and MS

- MS does not impair fertility in women
- Planned pregnancy is best
- Disease modifying treatments (DMT) are not recommended during pregnancy
- Mode of delivery has no effect on MS course


MS During Pregnancy

- The number of exacerbations or relapses are reduced during the last trimester of pregnancy by 70%

- Studies indicate MRI activity may be suppressed in late pregnancy

Living Well
Dimensions of Wellness

- Environmental
- Physical
- Intellectual
- Social
- Spiritual
- Emotional

Successful Living

- Stay involved
- Be realistic
- Maintain strong bonds with family and friends
- Positive health perceptions
- Reduce stress
- Set goals
- Talk about feelings
- Relaxation and fun activities
- Take control: empowerment!
- Sense of **Hope**