

Welcome to...

real
talk

real
answers



*living with **ms** in your 20s and 30s*

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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

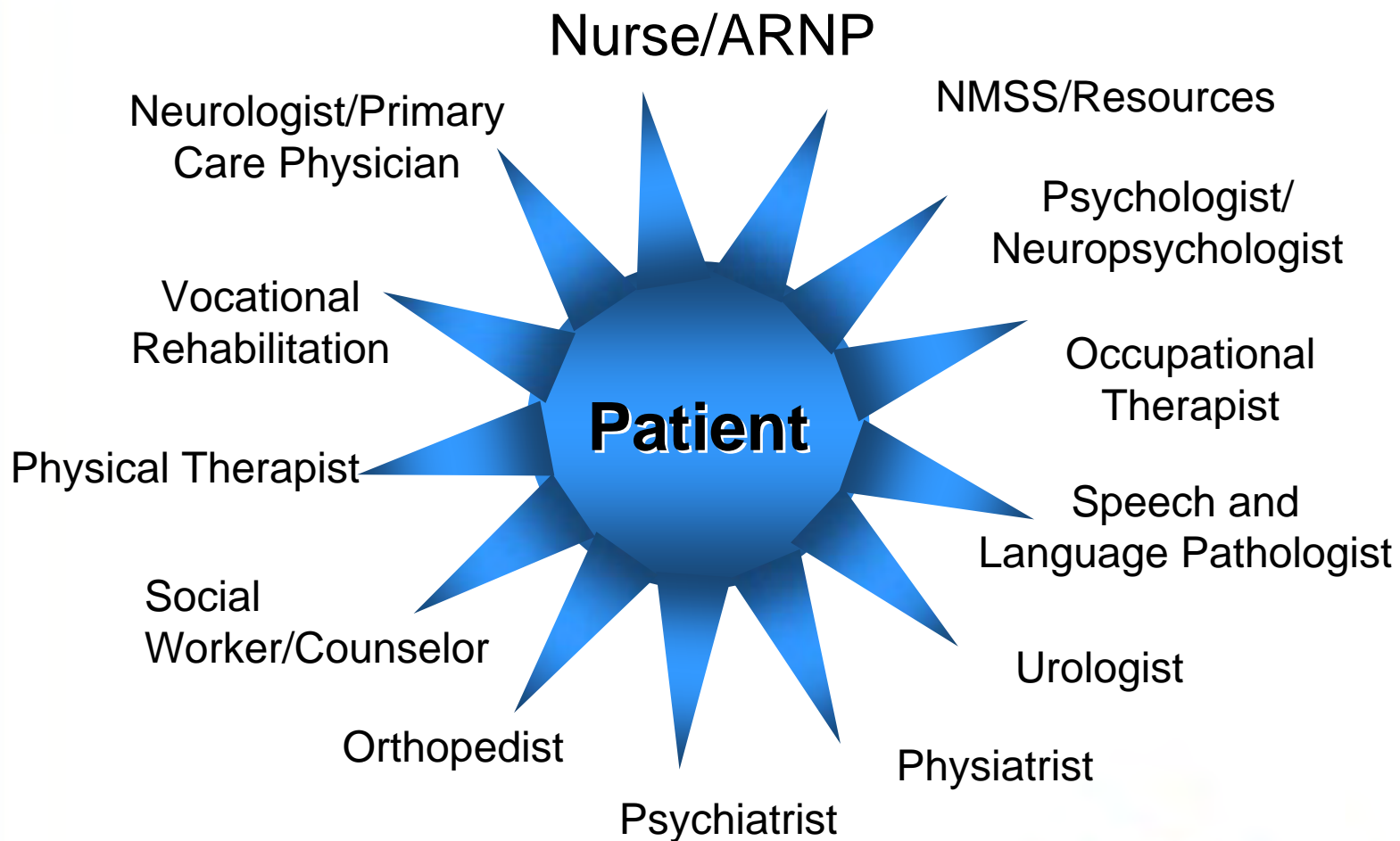
- **Each person's response is unique**
 - **Uncertainty and anxiety**
 - **Adaptation and adjustment**
 - **Grief**
 - **Re-emergence**

- **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!

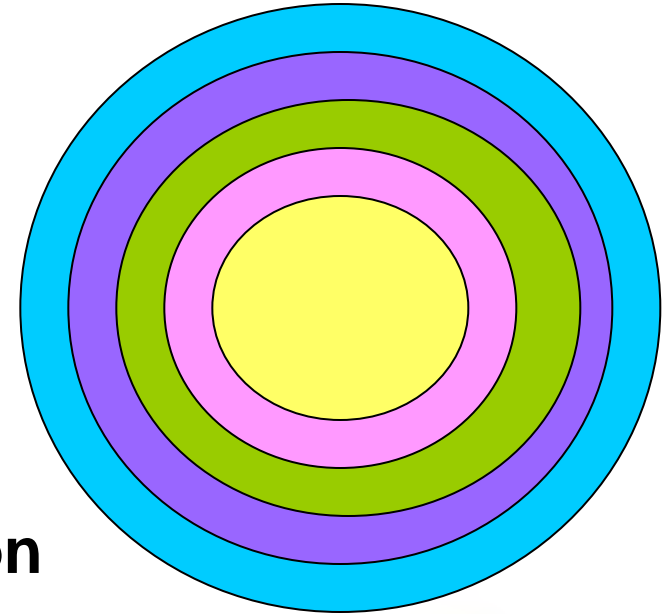


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Who, When and How to Tell!

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

- **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.

Kalb, R. (2006). In *Multiple Sclerosis: A guide for families*, 3rd Ed.



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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**

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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. (2006). In *Multiple Sclerosis: A Guide for Families, 3rd ED.* ; NMSS Real Talk, Real Answers: How MS Effects Intimacy, Peggy Crawford.
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



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

Tullman, M. 2004. *Symptomatic Therapy in MS*. Continuum: Multiple Sclerosis. Vol. 10. Number 6.
Costello K et al, eds. *Nursing Practice in Multiple Sclerosis: A Core Curriculum*. New York: Demos; 2003.
Foley, F. (2006). In *Multiple Sclerosis: A Guide for Families, 3rd ED.*; Foley, F. (2001). In *Multiple Sclerosis*. 7(6). Rehabilitation of Sexual Dysfunction in MS.



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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Foley, F. (2006). In *Multiple Sclerosis: A Guide for Families, 3rd ED.*; Foley, F. (2001). In *Multiple Sclerosis*. 7(6). Rehabilitation of Sexual Dysfunction in MS.



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**

Tullman, M. 2004. *Symtomatic Therapy in MS*. Continuum: Multiple Sclerosis. Vol. 10. Number 6.

Heran, M., Hohol, J. et al. (2000). Oral contraceptives and the incidence if multiple sclerosis. *Neurology*, 55:848-854

Birk, K. & Giesser, B. (2006). Fertility, Pregnancy, Childbirth, Chapter 5, page 82. In *Multiple Sclerosis: A Guide for Families*, Kalb, R.

Birk, K. & Giesser, B. (2006). Fertility, Pregnancy, Childbirth, Chapter 5, pages 81-83. In *Multiple Sclerosis: A Guide for Families*, Kalb, R.



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**

Birk, K. & Giesser, B. (2006). Fertility, Pregnancy, Childbirth, Chapter 5, pages 81-83. In *Multiple Sclerosis: A Guide for Families*, Kalb, R.

Kalb, R. & LaRocca, G. (2002). Sexuality and Family Planning, Chapter 7, pages 136-137. In *Comprehensive Nursing Care in Multiple Sclerosis*. Halper, J. & Holland, N., Eds.



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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**

Coyle, P. (2002). Gender Issues in Multiple Sclerosis. In *Multiple Sclerosis 2*, pages 259-283. W.I. McDonald & J. Noseworthy.

Birk, K. & Giesser, B. (2006). Fertility, Pregnancy, Childbirth, Chapter 5, pages 81-83. In *Multiple Sclerosis: A Guide for Families*, Kalb, R.

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Living Well



Dimensions of Wellness



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**

