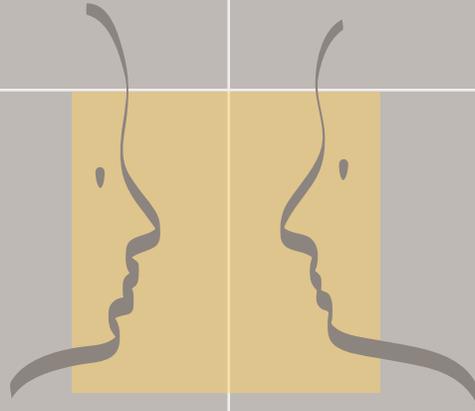




National
Multiple Sclerosis
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*Talking with Your
MS Patients about
Difficult Topics*



Talking about Reproductive Issues

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Professional Resource Center

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The National MS Society's Professional Resource Center (PRC) has long been a resource for health professionals providing care to people with multiple sclerosis. The PRC, which houses a comprehensive library of MS information, provides continuing education opportunities and offers multidisciplinary expertise on MS disease process and management questions, health insurance issues, long-term care options, and the development of MS specialty clinics. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis.

Physicians are invited to consult via email with MS specialist colleagues who serve on our National Clinical Advisory Board

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Introduction

This booklet is designed to facilitate conversations with your patients about reproductive issues. The majority of persons with MS are young, pre-menopausal women. In this population, questions regarding fertility, pregnancy, childbirth, and contraception—and their interaction with disease activity and disease-modifying therapy—are of paramount importance. Young men who are considering becoming parents also have concerns about this issue.

Like other topics in this series, this may be one that patients are reluctant to talk about

with their doctors and other healthcare professionals, particularly if they anticipate negative or distressing answers. Patients and their partners may not know the right questions to ask or when to ask them. The physician and nurse have an important role to play in initiating the discussion and providing timely information and referrals. The following information will help you communicate with your patients about this topic, in terms that are easily understood.

1. How and when should I address the topic of reproductive issues and MS?

- Reproductive issues should be addressed early after diagnosis.
- Newly-diagnosed young adults, who may be making important family-planning decisions in the near future, need accurate information about how MS might affect fertility, pregnancy, childbirth, and contraception.
- Since family planning decisions affect the use of disease-modifying agents (DMAs), the best strategy is to raise the issue as soon as you begin discussing treatment. If the patient has no imminent plans to start a family, the topic may be deferred until it's more relevant. However, remind your female patients to consult with you about all their medications *before* trying to become pregnant.
- The best venue for these discussions is during an office visit, ideally with the woman and her reproductive partner both present.

2. What is the most important information for me to give my patients about reproductive issues and MS?

- In general, couples should be reassured that MS is likely to have little effect on their reproductive capacity, and that pregnancy itself should not negatively affect the woman's long-term MS prognosis.
- MS does not increase the risk of miscarriage, congenital malformations, or infertility.
- Two recent studies have suggested that babies born to women with MS may tend to have slightly lower birth weights, but more research is needed to confirm these findings.
- For a woman with MS in otherwise good health, pregnancy, labor, and delivery can be managed routinely, posing no greater risk than in a woman of similar health status without MS.
- In women with relapsing-remitting MS, the relapse rate falls by approximately 66% during pregnancy. There is a sharp rise in relapse rate in the first 3–6 months post partum, followed by a return to pre-pregnancy levels.
- Nursing does not appear to be associated with increased relapse rate. However, any

decision regarding breastfeeding must take into account the medications a woman needs to resume taking for disease or symptom management. A recent pilot study suggested that women who breastfeed exclusively (without supplemental feedings) for at least the first two months are less likely to have a post partum relapse than those who do not breastfeed or do not breastfeed exclusively. A larger study is needed to confirm these findings.

- An important consideration for patients to take into account when making family planning decisions is the uncertainty of MS and the possibility of future disability,

with its accompanying impact on finances, family roles, and the physical ability to care for a child.

- The couple should be made aware of the high incidence of depression in people with MS, which may increase the likelihood of post partum depression. Depression during or following a pregnancy can affect a woman's ability to care for herself and her baby. Any woman who experiences depressive symptoms during or following her pregnancy should talk with you promptly so that you can make the appropriate referral for treatment.

3. Are there any special considerations regarding contraception that should be considered?

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- Because MS does not affect fertility, women with MS and their partners need to make the same decisions about contraceptive use as anyone else.
- Studies to date do not indicate either an increased or decreased risk of MS associated with oral contraceptive use. However, some of the medications that are used to treat MS, including steroids, anticonvulsants, or antibiotics, can interfere with the effectiveness of oral

contraceptives. Women should be encouraged to consider a dosage adjustment and/or the use of additional protection while taking any of these medications.

- Some women with impaired use of their upper extremities or decreased sensation may have mechanical difficulty using barrier methods of contraception, such as a diaphragm.

4. Do the disease-modifying agents (DMAs) or symptomatic therapies have an impact on fertility, pregnancy, delivery and/or the post-partum period?

- Of the first-line, injectable medications, the beta interferons are FDA Pregnancy category C agents (having been associated with miscarriages in primates), and should be stopped 1–2 months prior to attempting conception. Information about the pregnancy registries for the beta interferon products is available at www.nationalMSSociety.org/PregReg.

- Glatiramer acetate is a category B drug (no harm has been demonstrated in animal models, but no human data are available). Many, but not all, neurologists recommend stopping glatiramer acetate prior to conception.
- Women who are under consideration for treatment with the immunosuppressant agent mitoxantrone (a category D agent),

should be advised that the drug may cause amenorrhea, which is permanent in a small percentage of patients, and may cause fetal harm. The FDA labeling of mitoxantrone recommends that women of child-bearing age be given a pregnancy test prior to each administration of the drug.

- Natalizumab is a category C agent and should be stopped prior to attempting conception.
- In women with active disease, it may be appropriate to defer attempting pregnancy until disease activity is under satisfactory control.
- Studies indicate that those women who have had more relapses prior to pregnancy, are more at risk for developing post partum relapses. Therefore, the urgency of re-starting the DMA after delivery may depend on the patient/s pre-pregnancy relapse rate, and her desire to breast-feed.
- It is not known if any of the DMAs are excreted in breast milk; therefore, women who are nursing should discuss their medication options with their obstetrician and/or neurologist and pediatrician.
- Many symptoms of MS may become more prominent during pregnancy, including constipation, urinary urgency and frequency, and fatigue, as well as gait difficulties as the pregnancy progresses and the center of gravity shifts. These symptoms can be managed conservatively with rehabilitative strategies, and medication—if needed, following consultation with the obstetrician and/or neurologist and pediatrician.
- Some symptomatic therapies for MS, such as anti-spasticity agents, anti fatigue drugs, and medications for bladder control are category C drugs, and their use during pregnancy should be discussed with the obstetrician and/or pediatrician.

5. Are there any special considerations for labor and delivery?

- Labor and delivery are generally not affected by a woman's MS; all forms of anesthesia are considered safe for women with MS.
- Because a woman with prominent spinal cord involvement and weakness or loss of sensation below the waist may not be able to feel contractions, or be able to push effectively, she may require additional assistance during labor and delivery.
- Women with MS do not need exogenous steroids during labor and delivery, unless they have been on chronic steroid treatment.

6. What is known about the impact of the menstrual cycle and menopause on MS?

- A small number of self-report studies suggest that some women with MS experience an increase in neurologic symptoms in the few days before the onset of menses.
- There are very few data on the effect of menopause on MS.

7. Are there any issues regarding reproductive health for men with MS?

- Male fertility does not appear to be impaired in MS, although some men may have problems with impotence or ejaculatory dysfunction that interfere with conception. These problems are often amenable to a variety of therapeutic strategies, including medication for erectile dysfunction, artificial insemination, and electronic ejaculatory stimulation.
- To date, there are no published data concerning the impact of the disease-modifying therapies on conception or fetal development when it is the father who is taking the medications. Since the impact on spermatogenesis and fetal development has never been studied, men should be counseled about the possibility of stopping their medication while trying to conceive.
- For those men who take any of the immunosuppressant medications, including mitoxantrone (Novantrone), it is advisable for them to freeze sperm for future use in the event that the medication causes partial or complete sterility.

8. What shall I tell patients regarding the risk of their children developing MS?

- Epidemiologic surveys have determined that an individual's risk of developing MS increases several-fold if a close family member has MS. While the average person in the United States has about 1 chance in 750 of developing MS, the risk for a person who has a parent with MS increases to 1 in 40 (with the risk being higher for girls than boys). Thus, the risk increases significantly for a person whose parent has MS, but still remains relatively low.
- Risk estimates can vary greatly depending upon the structure of a person's family. In families in which MS occurs in many relatives, the risks for any given individual are significantly higher than they are for an individual who has no family members with MS.
- Risk for MS is also affected in part by a person's ethnic background and other factors that haven't yet been clearly identified. MS is more common in Caucasians of northern European background than in other groups.
- While genes are important determinants of a person's risk for MS, they are not the only factor. The identical twin of a person with MS has a 1 in 4 chance of developing the disease (with the concordance being higher in female twins than in male twins). The findings that identical twins of people with MS who share all the same genes do not always get MS, and that more than 80% of people with MS do not have a first-degree relative with MS, demonstrate conclusively that MS is not directly inherited and that factors other than genetics must be involved.
- Couples who express concerns about the genetic risk for their children should be told that the risk is relatively low. However, at the present time, there is no genetic testing available to provide them with a definitive answer.

9. How can I help my patients deal with some of the emotional issues related to this topic?

- Young men and women with MS face the additional stress of a chronic, unpredictable disease when making family planning decisions. Encourage your patient and his or her partner to talk frankly with each other about:
 - Their personal priorities and needs
 - The strength and flexibility of their relationship
 - The availability of a support system
 - Their financial resources
 - Their parenting and child-rearing goals and ideals
- Encourage your patients to think through the negative as well as the positive possible outcomes—e.g., if the parent’s disability were to progress significantly, or if the parenting and wage-earning roles and activities were to require some adjustments.
- Encourage your patients to think beyond the initial few weeks or months of a child’s life. Remind them that too often, prospective parents focus on bringing the baby home from the hospital, forgetting that babies grow rather quickly into very active children and busy teens.
- Encourage couples to think through possible strategies and resources for dealing with future disease-related changes.
- If you feel that your patient and his/her partner are struggling with these issues, refer the couple to a family therapist familiar with MS, who can help partners express their feelings and concerns with one another, identify options, and develop effective communication and problem-solving strategies. The National MS Society can provide referrals to counselors who are familiar with the challenges couples and families with MS may face.

10. What resources are available to support my patient?

- Chapters of the National MS Society (1-800-344-4867) offer:
 - *Relationship Matters* program—a series of interactive classes for couples living with MS
 - Educational programs and support groups
 - Referrals to professionals in the community who specialize in the treatment of sexual dysfunction and family issues
 - Printed materials about sexuality and a range of other topics available free of charge (also available from the National MS Society website: www.nationalMSSociety.org/Brochures)
 - *MS and Intimacy*
 - *Fatigue: What You Should Know*
 - *Taming Stress in Multiple Sclerosis*
 - *Multiple Sclerosis and Your Emotions*
 - *Controlling Bladder Problems in Multiple Sclerosis*
 - *MS and the Mind*
 - *Talking about Sexual Dysfunction*
 - *Sobre los Problemas Sexuales Que No Mencionan los Médicos*
- National MS Society website (www.nationalMSSociety.org) offers information on a wide variety of topics (e.g., disease-modifying therapies, symptom management, research), as well as access to local resources and events.

- Information on MS and Intimacy.
www.nationalMSSociety.org/Intimacy

- **Additional recommended websites:**

- Multiple Sclerosis Society of Canada.
www.mssociety.ca
- Multiple Sclerosis International Federation. www.msif.org
- Pharmaceutical Company Support Programs
 - Betaseron
BETAPLUS
www.betaseron.com
 - Avonex
MS Active Source
www.msactivesource.com
 - Copaxone
Shared Solutions
www.sharedsolutions.com
 - Novantrone
www.novantrone.com
 - Rebif
MS Lifelines
www.mslifelines.com
 - Tysabri—TOUCH
Prescribing Program
www.tysabri.com

- **Recommended reading:**

- Kalb R (ed.). (2006). *Multiple Sclerosis: A Guide for Families* (3rd ed.). New York: Demos Medical Publishing.
- Kalb R (ed.). (2008). *Multiple Sclerosis: The Questions You Have, The Answers You Need* (4th ed.). New York: Demos Medical Publishing.
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Barbara Giesser, MD is Associate Professor of Clinical Neurology at the UCLA School of Medicine. She received her BS from the University of Miami, an MS from the University of Texas at Houston, and her MD from the University of Texas Medical School at San Antonio. Dr. Giesser has specialized in the care of persons with MS since 1982, beginning with her training at the MS Research & Training Center of the Albert Einstein College of Medicine, under the direction of Dr. Labe Scheinberg.

Dr. Giesser has been the Medical Director of the Gimbel MS Center at Holy Name Hospital, Medical Director of the Rehab Institute of Tucson, and is currently an Associate Professor of Clinical Neurology at UCLA and Medical Director of the Marilyn Hilton MS Achievement Center at UCLA. She has published in the areas of cognition in MS, bladder management, and women's issues.

In addition to her clinical activities, Dr. Giesser has been active in developing educational materials about MS for medical student and residents, as well as client and professional education endeavors for the National MS Society.

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Dr. Benedetto-Anzai is currently the consulting gynecologist to the Initiative for Women with Disabilities Elly & Steve Hammerman Health & Wellness Center at NYU Hospital for Joint Diseases in New York City. She was the Center's Gynecologist from 2000–2005, during which time she was instrumental in developing and expanding the gynecology practice and ensuring that women with multiple sclerosis and other physical disabilities received high quality gynecologic care.

Dr. Benedetto-Anzai also maintains a private practice in New York City, which includes patients with physical disabilities.

Rosalind Kalb, PhD, is Vice President of the Professional Resource Center at the National Multiple Sclerosis Society in New York City, providing educational materials and consultation services for healthcare professionals. Dr. Kalb has authored or edited a number of National MS Society publications—the *Knowledge is Power* series for newly-diagnosed patients and the Cavallo Professional Education book series for health professionals. She has edited two books—*Multiple Sclerosis: The Questions You Have; The Answers You Need*—now in its 4th edition—and *Multiple Sclerosis: A Guide for Families*, now in its third edition. She is the senior author of *Multiple Sclerosis for Dummies*, and co-author with Dr. Nicholas LaRocca of *Multiple Sclerosis: Understanding the Cognitive Challenges*.

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