

SEX

MS vs. good sex

by Martha King

Pat Kennedy, certified MS nurse practitioner, has been talking to people with MS about their sex lives for over two decades. At The Heuga Center's "CAN DO" program, she offers 45-minute sessions one-on-one (or with a couple), in addition to many conversations at the Rocky Mountain MS Center where she also practices. Once she closes the door, fixes her twinkling Irish eyes on someone, and begins asking straight questions in her level low-key way, stories spill out. In all that time, she said, the stories are seldom about MS symptoms alone. Problems in bed are almost always problems involving life with MS and the stress MS puts on relationships.

What MS can do to sex life has a huge impact on the quality of life overall. We start this section with a veteran health-care provider's view.

Early on, people are wondering how they can live with MS and dreading what it might do. Fear is a great squelcher of sexual desire. Moreover, newly diagnosed people often feel their self-esteem is so challenged that intimacy is difficult. Later on, people are busy. They're "busy" being fatigued, "busy" coping with symptoms. There's a great deal to think about and all too often their partnerships and their love life take a back seat. Communication declines and often the well partner feels, "This just isn't the person I fell in love with." When cognitive problems or overwhelming feelings of guilt and anger are in the mix, this isn't so surprising.

The real issue

"Talking about sex is particularly hard to do," Pat Kennedy told **Momentum**. "People don't have good models for it. People just aren't comfortable with the words, despite all the stuff you see in magazines. Some people can break through and do it on their own. Some people need help. Either way, everyone needs intimacy, and intimacy is the real issue. Or put another way, when you have sex without intimacy, the whole brilliance goes."

Martha King is editor of **Momentum**.

"I was so flattered when I heard a rose had been named after me until I read the description in the catalog: 'Not good in a bed, but excellent standing against a wall.'" —Eleanor Roosevelt



ILLUSTRATIONS BY ELWOOD SMITH

Real-life sex with MS

by Patricia Wadsley

Intimacy means different things to different people. For some, it's a bouquet of flowers, a kiss on the cheek, or revealing a secret that brings you closer to another person.

For others, intimacy is simply getting naked under the sheets. For Michelle*—a wife, mother, and real estate broker with MS from Chicago, Illinois—intimacy was a bowl of soup.

One night as Michelle, 50, came home from work, she smelled simmering spices and meats wafting under the door. Her husband, Jim, had expected her to be tired. He had never made a meal in his life, but on this night, he had made her soup.

"It was foreplay," she said. "It was like an aphrodisiac."

That soup had been a long time coming. Michelle had been diagnosed seven years before, and for the first three, she and Jim had led virtually separate lives.

"Let's be honest," Michelle said. "My husband and I had been married a number of years. Our sex drives were much lower than newlyweds."

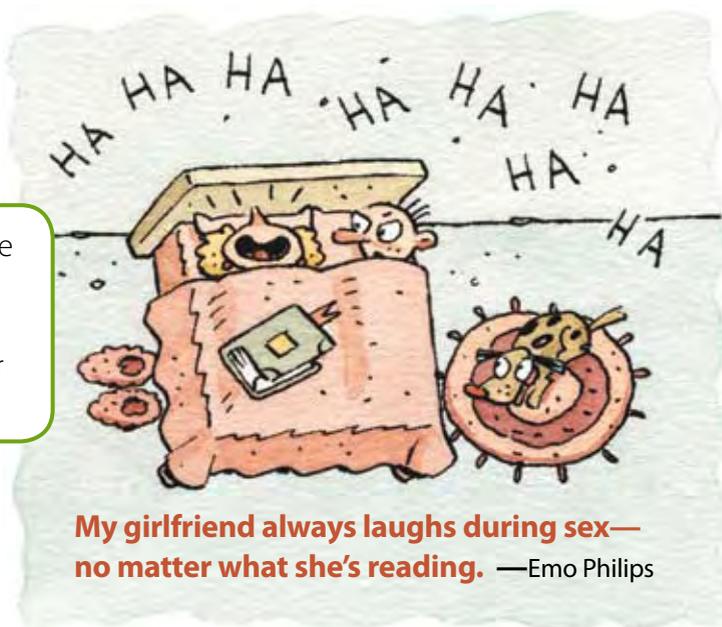
After she was diagnosed, things got worse.

"Suddenly, I wasn't moving the same. I was fatigued, taking test after test, and juggling medications," she said. "The last thing I wanted was to have to deal with another person."

"I wound up wearing sweats for two years, even to bed," she said. "I felt unattractive, and

*The couples interviewed for this article preferred to remain anonymous. All of their names have been changed.

Two people with MS talk frankly about their love life.



My girlfriend always laughs during sex—no matter what she's reading. —Emo Philips

made sure I looked unattractive, too. I never told my husband how bad I felt. I didn't want to complain. I was a woman who could do it all. How could I admit I was vulnerable?"

Her husband shut down too.

"Only when I found the right medication for me, and started feeling better about myself, did I start getting that skin hunger again," Michelle said. "I started getting massages and taking baths, and each day my body was waking up sensually.

I wanted my husband, but by that time we were a million miles away from each other. Finally I poured out my feelings to my doctor."

Communication is key

Supported by her doctor's advice, Michelle started telling her husband about MS and its symptoms, especially the hidden ones. "I started telling him what I was going through," she said. "I told him I was in pain. He seemed frightened at first. At one point, I wasn't even sure if he was still listening. But I did not want him to feel rejected."

Not long after, she came home from work to discover the

Barriers to good sex

- Numbness or less feeling in the genitals
- Taking too long to climax
- Less intense pleasure at climax
- Feeling less attractive overall

for men

- Difficulty getting or keeping an erection
- Less confidence in ability

for women

- Less desire
- Less lubrication

soup. Jim had also vacuumed. “I knew he’d listened to me,” she said. “I fell in love again.”

Throw the book away

From that day on, Michelle was empowered. “I knew there were certain physical things I could no longer do,” she said, “but I began to think, what can we do instead? Can we do it another time?” She and Jim talked honestly, maybe for the first time in years. “He knew I didn’t want sex right away, so we started cuddling.” And then they really started getting into it. “We have sex early in the day—never at night, when I am too tired,” she reported. “And if I’m tired and I fall asleep, sometimes that’s an orgasm to me. My husband says, ‘You owe me one, turkey!’”

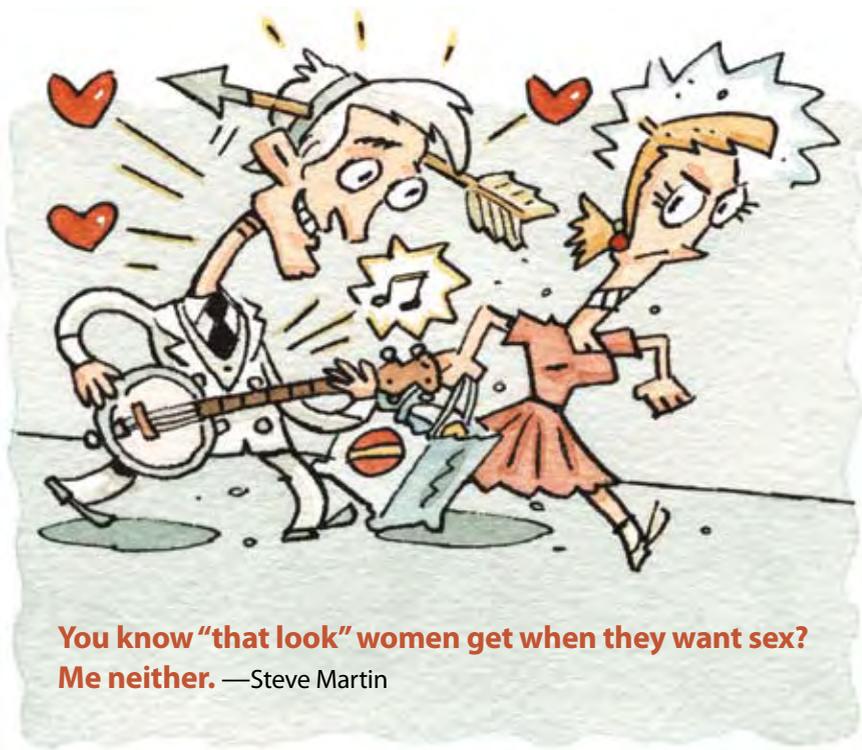
“We had to relearn how to be with each other,” said Michelle. “And for the first time in years, a playfulness has returned to our lovemaking. If I have numbness, we think, what else can we do under the covers? Sometimes, we just want to be close to each other and laugh.

“My husband even learned how to give massages to me. We had to find our way to closeness. And now that we have, we may be closer than ever before.”

Creative solutions

Although Jack, 37, an artist from Ohio, won’t go as far as to say sex has gotten better, he will admit that it is becoming another creative outlet. Jack had an active sex life over the years and was determined not to lose it when MS entered his life.

“I had been diagnosed for a few years before I met my fiancée, Emma,” he said. “There were no surprises, but I did go through the poor me’s. I knew that sex would be more difficult, but she assured me it was her decision to be with me, and to get over it. We were fortunate to be able to communicate with each other.



You know “that look” women get when they want sex? Me neither. —Steve Martin

“I’ve actively explored aids and techniques that enhance sex even if you have a disability,” Jack said, “so I now know how to deal with fatigue, erectile dysfunction, slow arousal, numbness—the whole laundry list of things.”

Throw away your inhibitions

One answer Jack found was toys.

“I am all for sex toys,” Jack related. And so are very serious MS specialists, such as Dr. Frederick Foley. Cultivating humor and playful attitudes helps build trust and intimacy. Jack also recommended mint K-Y jelly which increases sensitivity as well as lubricates, so it works on the numbness.

And he studied Tantric sex, starting out with the **Kama Sutra**. “It slowed me down and made the pacing steady and consistent. The continuity enables me to achieve orgasm more consistently. And we have a vibrator for Emma. Vibrators are the way to go.

“I admit that some of it may seem a little crazy,” Jack said, laughing. “But sex is inherently funny. You might as well have a good time with it.”

Patricia Wadsley is an associate editor of this magazine.

Rethinking sex

by Marcella Durand

In 21st-century America, **sexy** is usually defined as young, buff, healthy, and—did we say young? In movies, television shows, and novels, energetic men and women fall into each other's arms to have spontaneous, on-the-spot intercourse, with everyone quickly reaching a wild climax.

This popular image can be at odds with the realities of nearly everybody, and especially people living with MS. Most bodies and desires don't exactly conform to our culture's expectations of what and who is sexy.

Enjoying the journey

Momentum spoke to two physicians who direct clinics for people with MS. In addition, Vincent Macaluso, MD, has lived with MS for over 20 years.

"Society places a high value on orgasms, leading many couples to focus on this as the ultimate goal of sex, when in truth it is the journey of intimacy that is the most satisfying," said Salvatore Napoli, MD, 34, medical director, New England Comprehensive MS Program at Caritas Norwood Hospital and Foxboro in Massachusetts.

Our achievement-oriented society likes to be able to measure success, and an orgasm is a convenient way to do that. But a world of wonderful sensations can get lost along the way, he thinks.

"Sexual satisfaction comes from so many things—it's the courtship, the give-and-take, learning about the person, seeing what they like, where they go, the subtle things that turn it into such a beautiful dance," said Dr. Macaluso, 39, who directs the Macaluso MS Infusion Center in Great Neck, New York. "When you view sex like that, by the time it comes to orgasm, you're already spent."

The biggest sexual organ

As the old joke has it, the brain is the biggest sexual organ. But there is no "sexual center" in the brains of men or women. Instead, different areas of the

Our experts suggest you can create your own definition of sex—one that isn't dictated to you by others. You need a little willingness to change your thinking.

brain participate in sex drive, sexual stimuli, pleasure, and sensation.

Talking with your partner may be the best place to turn on your brain. And you don't have to talk about sex to set the mood. Share the day with each other: gossip, laugh, tease.

"One of my professors said the most important word in sex is a four-letter word that ends in K—**talk**," Dr. Macaluso said.

Mapping your body

Just like the brain, there's no one center of sexual pleasure in the body. While "private parts" may get all the attention, other areas can be equally open to pleasure. For instance, you might enjoy having your feet massaged. (In fact, this has a basis in biology. According to Dr. Macaluso, some of the same nerve routes supply sensation to both the genitals and the feet.)

"Body-mapping" is a technique developed by Dr. Frederick Foley (see page 50). The idea is to familiarize yourself with your own body—which MS may have changed. In a private, relaxing place such as a bedroom, touch your body wherever you can. Using what you learn, have your partner slowly touch you head to toe. Take time to find out where exactly you have decreased or altered sensation, and where you respond.

Exploring alternatives

Another avenue to explore is Tantra, better known as Tantric sex.

Like yoga, Tantra originated in India centuries ago. Its focus is not on orgasm or "improving your sex life." Instead, in Tantra, the spirit is seen as more important to sex than the body. The purpose of the sexual act is to increase awareness, not to reach orgasm. Breathing exercises and concentrating on

specific body parts, such as the hands, are just two Tantric techniques.

For more information about Tantra, visit sexualhealth.com and search for “Tantra.”

Be open to change

“It’s important for people with MS and their partners to share their feelings about sexuality, especially as these feelings change throughout a relationship,” Dr. Napoli said.

What you found sexy yesterday may not be what you find sexy today—or tomorrow.

Getting help

If you’re having trouble expressing newfound desires to your partner—whether for soup, a foot massage, or spending time in bed in the morning when energy is highest—try talking with a health-care provider or a counselor. You may feel embarrassed at first, but you shouldn’t worry. “We can find ways to help,” said Dr. Napoli.

Marcella Durand is an associate editor of **Momentum**.

A checklist of symptom tamers

- Work with health-care providers to control symptoms such as spasticity or medication side effects. Bladder problems can be managed. Timing can help with fatigue, medication side effects, even cognitive problems.
- Inject romance. Cultivate humor and imagination. You and your partner will get off on candles, flowers, and music. There’s a reason these are old standbys. Even if you’ve been together 25 years, make a date, play a game!
- Explore new approaches, styles, or positions. There are many ways to give and receive pleasure.
- Get some help learning how to talk about “it.” Your health-care provider or Society chapter can refer you and your partner to

counselors, psychologists, or gay/lesbian health organizations. Counseling, spiritual practices, and peer groups may all contribute to bringing intimacy with your partner back into your life.

- Men, talk to your doctor about ED medications. (They don’t help women.) And ask a urologist before trying any devices.
- Plan to give yourself a special treat every day: use a great skin lotion or hair conditioner, experiment with aromatherapy, buy yourself a flower, or make a special time for music, meditation, or prayer.
- Explore personal lubricants. Liquids usually work better than gels, and there are warming and scented liquids to try out. Use liberally, and encourage your partner to participate.
- Vibrators are highly recommended. Give yourself and your partner permission to have fun finding out what works best.
- Confidence and self-image are not easy issues. A chronic disease diagnosis knocks a huge hole in a person’s world view. Rebuilding may require exploring all kinds of questions—deep ones, like the meaning of life, and immediate ones, like how long do I date someone before I talk about my MS.



Resources for good sex

WEB

More information is available on the Society's Web site, on a page called MS and Intimacy: nationalmssociety.org/Intimacy.

The Society has also published a brochure on MS and intimacy, which can be downloaded at nationalmssociety.org/download.aspx?id=152, or call 1-800-344-4867 and request a copy.

The Sexual Health Network: sexualhealth.com. Information on sexuality for those with disabilities and illnesses. It also provides links to other resources and offers live broadcasts.

The Sinclair Intimacy Institute: sinclairinstitute.com. Catalog of adult sex education videos

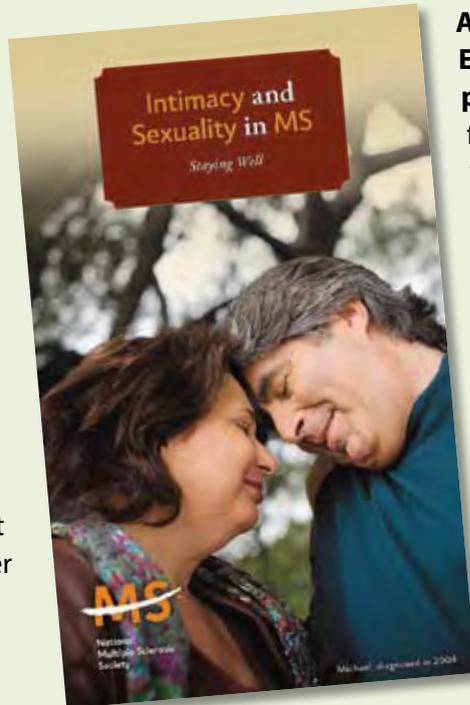
DivorceBusting.com. Offers help for sexually troubled marriages

The Marriage & Family Health Center: passionatemarriage.com Offers sexuality education and therapy programs

BY MAIL

Sexuality Information and Education Council of the United States (SIECUS) provides a bibliography of print and audiovisual materials on sexual-

ity and disability for \$3.00. Call 212-819-9770 to order by phone or write: SIECUS, 90 John Street, Suite 704, New York, NY 10038. The bibliography can be downloaded free at siecus.org.



American Association of Sexuality Educators Counselors and Therapists (AASECT) provides a list of certified sex therapists and counselors in your area. Go to aasect.org/directory.asp or send a self-addressed, stamped envelope to: AASECT, PO Box 1960, Ashland, VA 23005-1960.

The Xandria Collection publishes a catalog of sexual aids, toys, and books. Call 800-242-2828 or visit xandria.com.

Good Vibrations has a free mail-order catalog of sexual aids, books, and videos. Visit goodvibes.com, call 800-289-8423, or write to them at 938 Howard Street, Suite 101, San Francisco, CA 94103.

Learn more about intimacy from Relationship Matters

When people say "intimacy," what exactly do they mean? Find some answers in the Society's free online course, **Intimacy: Enriching Your Relationship**. The course, part of **Relationship Matters: A Program for Couples Living with MS**, focuses on improving intimacy in relationships, not just in bed. Participants explore how to make a personal definition of intimacy, strategies for communicating about tough issues, and ways to manage the effects of MS on sexual function. The course is private and self-paced—participants can stop and pick up again where they left off. To register, e-mail couplesprogram@nms.org, or call **1-800-344-4867**.

New study ranks barriers to good sex

by Gary Sullivan

A groundbreaking study of sexual dysfunction in people with MS reveals that most people with the disease contend with at least one symptom of sexual dysfunction.

The results of this study—the first large-scale investigation in North America, and the largest in the world—were presented by Dr. Frederick Foley at the 21st Annual Meeting of the Consortium of Multiple Sclerosis Centers in Washington, DC, last summer. Dr. Foley is the director of Psychosocial Research and Neuropsychology at the MS Center at Holy Name Hospital in Teaneck, New Jersey.

“We surveyed 8,361 people with MS using the Multiple Sclerosis Intimacy and Sexuality Questionnaire, or MSISQ,” Dr. Foley told **Momentum**. “Of those surveyed, 5,868 responded. Those who completed the survey tended to skew younger, less neurologically impaired, and wealthier—so we believe the results may be conservatively biased,” he explained.

Dr. Foley developed the MSISQ seven years ago with a graduate student, Audrey Sanders, and two small grants from the National MS Society; the questionnaire was subsequently published in **Sexuality and Disability** (Volume 18, Number 1, 2000).

Research confirms that sexual problems are common to many and deserve attention as much as other MS symptoms.

What the survey said

Nearly 70% of responders (67.2%) said that they had at least one or more MS-related symptom that interfered with sexual activity or satisfaction “always” or “almost

always” during the last six months.

Slightly more than half of the men reported difficulty getting or keeping an erection and a third or more said that they felt less confident about their sexuality, were having less pleasurable or intense orgasms, were taking too long to climax, and/or were feeling numbness in their genitals.

Nearly 40% of women said they took too long to orgasm, and more than a third of women felt less intense or pleasurable orgasms, experienced a lack of sexual desire or loss of libido, and/or had inadequate vaginal lubrication. The number who reported loss of feeling or numbness in the genitals was just under one third.

A surprising discovery

“One response we received ran counter to general expectation,” Dr. Foley said. “Nearly a quarter of the men reported feeling that their body is less attractive, while slightly less than one fifth of women responded similarly.

“We’re now analyzing all of the study results to determine what sort of impact these barriers may have on quality of life. And we’ve decided to develop a study into the body image question.”

Dr. Foley’s survey was sponsored by the Consortium of Multiple Sclerosis Centers (CMSC) and conducted through their North American Research Committee on Multiple Sclerosis (NARCOMS) registry. To learn more about the CMSC, NARCOMS, and to register, visit mscare.org/cmssc/CMSC-NARCOMS-Information.html.

Gary Sullivan is **Momentum’s** managing editor.

Sex is one of the nine reasons for reincarnation. The other eight are unimportant.

—George Burns

