

Intimacy and Sexuality in MS

STAYING WELL



National
Multiple Sclerosis
Society

Michael (front cover), diagnosed in 2004.

Intimacy and Sexuality in MS

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Introduction

What does **intimacy** mean? For many people, the term is synonymous with sex — in other words, being intimate with another person means having a sexual relationship. However, a satisfying, intimate relationship rests on a much broader foundation of trust, open and honest communication, shared goals and expectations, and mutual respect and concern. So intimacy refers to all of the ways, both verbal and non-verbal, in which partners connect with one another and enjoy their unique closeness.

This booklet discusses some of the ways in which MS can affect intimacy between partners — by bringing about changes in the roles and responsibilities in the relationship; disrupting people’s plans and expectations for the future; changing sexual feelings and responses; and making it harder to share uncomfortable feelings and fears. Changes in any or all of these areas of daily life can affect a relationship’s delicate balance.

While the challenges may at times feel overwhelming, many couples have found successful and satisfying ways to deal with the intrusion of MS in their lives. In fact, confronting the challenges of MS draws many partners closer together, deepening their sense of connectedness and commitment. So in addition to alerting you to some of the barriers that MS can create for couples, this booklet will also give you helpful pointers on how to work around them.

Taking a Look at the Challenges to Intimacy

- **MS is like a “third wheel.”**

For many couples, MS becomes like a third wheel in their relationship — an annoying presence that is always getting in the way or interfering with plans and activities. The best way to hold on to feelings of intimacy is to make sure that you and your partner are always functioning as a team — working together to adjust and adapt while making sure that your feelings of frustration are directed at the MS rather than each other.

- **MS changes the “rules.”**

MS has a way of turning things topsy-turvy. “This isn’t the way life was supposed to be” is a common reaction among couples whose daily lives have been changed by MS. When shared expectations and dreams are threatened by a chronic illness, partners can team up to identify “work-arounds” — tools and strategies that allow them to pursue their shared goals and avoid blame and guilt. Creativity, flexibility, and a good sense of humor seem to be the key ingredients for making things work when life hands you something other than what you bargained for.

- **MS introduces uncertainty into everyday life.**

No one can predict how MS will affect someone from morning to afternoon, let alone from one month or year to the next. This kind of unpredictability leads many partners to wonder, “What can we count on from each other?” and “What can we plan for today, tomorrow, and in the future?” Faced with this kind of unpredictability, partners can maintain a greater feeling of control by engaging in some joint planning and problem-solving, whether it’s a back-up plan for tomorrow’s family outing or

financial planning for the future. Planning for uncertainty is the surest way to feel more in control of the uncontrollable.

- **A chronic disease strains resources.**

MS can drain a couple of their valuable resources, including money, emotional energy, and time. People can be left feeling overwhelmed, drained, and resentful, particularly if other important needs go unmet. An intimate partnership thrives best when both persons' needs are recognized and important resources are shared. So the goal is to make sure that MS doesn't get more of the emotional and financial resources that it truly needs.

- **MS can interfere with roles and responsibilities.**

In long-term relationships, partners tend to split up the jobs and responsibilities that keep everyday life on track. When MS makes it difficult or impossible for one partner to carry out some of his or her responsibilities, the other partner may need to pick up the slack. The trick to maintaining balance in a partnership is to make sure that responsibilities are swapped in such a way that both partners remain on the giving and the receiving end of things. If one partner begins to feel that he or she is no longer contributing to the relationship, and the other feels that he or she is carrying the full load, neither person will feel as though the partnership is working.

- **MS can make open communication more difficult.**

Talking about tough issues is never easy, and MS-related challenges are no exception. Neither partner wants to upset the other by talking about things that are scary or unpleasant, and most people tend to shy away from discussing problems that have no easy or obvious solutions. Yet finding ways to talk

openly about these challenges is the first step toward effective problem-solving and the feelings of closeness that come from good teamwork. Couples counseling is an ideal setting for starting some of these difficult conversations.

■ **MS can interfere directly and indirectly with sexual function.**

Difficulty with sex is quite common — in fact, more than 10 percent of men and women without any illness or disability report having at least some challenges where sex is concerned. And although study results vary somewhat, the data clearly indicate that people with MS report more problems with sex than people who don't have MS.

Fortunately, there are many sources of help and support. Primary care providers can usually start the process of identifying the source of problems and offer both medical and non-medical treatment options and/or referrals to specialists. But more often than not, the person with MS has to be the one to bring up the subject since most doctors don't routinely ask about it.

The key message here is that intimacy and sexuality are important components of a healthy and contented life. They do not have to disappear from the lives of couples when one partner has MS. Instead, partners can find satisfying ways to overcome the barriers.

The rest of this booklet looks at the kinds of sexual problems that can occur in MS. Knowing more about how MS can affect sexuality will make it easier for you take steps to deal with whatever problems or changes you are experiencing. The discussion starts with a review of the ways that MS can affect sexual feelings and functions, continues with some important

steps for getting any help that you need, and ends with a description of the treatments and strategies women and men can use to deal with whatever problems they encounter.

Understanding How MS Can Affect Sexual Function

MS can affect sexual feelings and functions both directly (referred to as **primary sexual effects**) and indirectly (referred to as **secondary** and **tertiary sexual effects**).

Primary sexual effects

The central nervous system (CNS) makes sexual arousal possible; the brain, sexual organs, and other parts of the body send messages to each other along nerves that run through the spinal cord. MS-related damage to these nerve fibers can directly impair sexual feelings or sexual responses in the same way that damage in the CNS can affect a person's ability to walk or see. And, just as with other aspects of MS, sexual problems can arise at any time.

The primary sexual effects, which occur as a direct result of demyelination (or loss of the protective myelin layer on nerve fibers) in the spinal cord or brain, include:

- Decreased or absent sex drive
- Altered genital sensations such as numbness, pain, or hypersensitivity

- Decreased vaginal muscle tone
- Difficulty or inability to get an erection
- Decreased vaginal lubrication and clitoral engorgement
- Difficulty with or inability to ejaculate
- Decreased frequency and/or intensity of orgasms

Secondary sexual effects

In addition to the changes caused directly by damage to the nerve fibers in the CNS, secondary problems can arise as a result of other MS symptoms or the medications used to treat those symptoms.

- Fatigue, a very common MS symptom, can suppress desire or make sexual activity feel overwhelmingly exhausting.
- Depression, which is one of the most common symptoms of MS, can increase a person's feelings of fatigue and decrease interest in sexual activity.
- Spasticity can interfere with sexual positioning or cause pain.
- Bladder and bowel disturbances can create some unique concerns. The thought of having a bladder or bowel accident during sex can stifle interest.
- Managing indwelling catheters can pose additional difficulties.
- Sensory changes (for example, numbness, pins-and-needles, and pain of various kinds) can make activities that used to feel good begin to feel very uncomfortable. Because physical contact is such an important part of intimate communication and simple pleasure, the loss can be devastating.

- Cognitive impairments, such as changes in attention and concentration, can also interfere with the buildup and progression of sexual excitement and feeling. Changes in attention or concentration can disrupt the emotional and behavioral interactions of sexual activity, producing a sudden loss of interest.
- Tremor in the hands or other parts of the body can interfere with physical and emotional communication between people.
- Side effects of various medications can interfere with sex drive or function.

Tertiary sexual effects

The tertiary effects on sexual feelings and responses result from psychological, social, and cultural attitudes and issues. In many ways, they raise the most difficult barriers to contentment in intimate and sexual relationships. And they can affect both the person with MS and his or her partner. Tertiary effects include performance anxiety and changes in self-esteem; depression, demoralization, and guilt; and family and social role changes or role conflict.

- Changes in body image can affect both the person with MS and the partner. Changes in physical appearance may damage people's image of themselves or their partner as a sexual being. Our society doesn't offer up many images of sexiness that include a cane or wheelchair.

- MS symptoms that come and go unpredictably and make a person feel out of control of his or her own body can have a negative impact on self-image and self-esteem. It is hard to feel sexy when you are experiencing a lot of fatigue and discomfort in your body.
- Grief, demoralization, anxiety and depression frequently accompany MS. These emotions affect both partners. They may cause feelings of isolation, interfere with desire, and lead both partners to stop thinking sexually.
- MS may change a person's roles in work, in running a household, in parenting, and in the activities of daily living. Sometimes these changes affect the person's ability to feel like an equal partner in the relationship. These changes can also be difficult for the partner without MS, especially if caregiving activities leave him or her feeling more like a caretaker than a sexual partner.
- Cultural values and expectations get in the way of intimacy and sexuality. Many ideas about "proper" or "normal" sexuality prevent people from exploring new ways of giving and receiving pleasure. Our society puts great emphasis on ejaculation and orgasm as the sources of sexual satisfaction. This goal-oriented approach to sex may make the pursuit of satisfaction a frustrating experience.

Taking Steps to Manage Sexual Problems

Step 1: Getting comfortable talking about “it”

Often the biggest problem is the inability to discuss sex and intimacy with one’s partner. In many ways, a discussion of personal sexual problems or preferences is still taboo in our society, despite a popular culture that seems to be steeped in sex. Not only is the subject embarrassing, but in many cases, we just don’t have the language to describe our feelings and experiences. Learning to talk more comfortably about sexual issues is a process:

Writing it down

It can help to start by putting pen to paper. What physical symptoms interfere with your intimate relations? Which of these symptoms is the greatest barrier? What feelings and associations do you have when you think about MS and your love life? Writing down your thoughts may help put the problems into language and start the difficult process of communicating. It may also help to clarify where the challenges lie, which is the first step toward a solution.

Sharing important information with your partner

Talk is the main way that we come to feel close to another person, perhaps because of how very difficult it is to talk to someone about personal things. We share our life stories, goals, fears and dreams only with special people.

When MS problems are in the picture, avoiding talk can easily lead to avoiding sex and other intimate contact. For example, sensory changes may make things that used to bring pleasure feel painful or uncomfortable — whether it's holding hands, getting a back rub or having intercourse. Telling your partner what feels good and what doesn't becomes crucial to intimate relations when MS changes the body and the mind. It's equally important to find out what your partner wants, particularly if the intimate activities you've previously enjoyed together are no longer possible. Without this kind of communication, your reluctance to hold hands, enjoy a cuddle, or engage in sexual activities can be easily misunderstood by a partner as loss of affection or interest.

Confiding in your partner actually deepens intimacy and may go a long way toward resolving fears. Here's another example: One common anxiety among people with MS is fear or shame about bladder or bowel accidents. Giving up sexual activity is not a solution to this. Talking over the problem with your partner can reduce the anxiety and discomfort for both of you, and talking it over with your healthcare professionals will produce some solutions. Bladder and bowel problems can usually be managed through medication and establishing regular eating and toileting schedules. With good communication, a little urine won't destroy a rewarding sex life. However, concealing the problem and the anxieties associated with it might.

The person with MS is not the only one who needs to talk about sexual feelings and anxieties. A partner's experiences are also affected by the MS. Communicating these feelings can help partners avoid guilt, grief, and resentment.

Cognitive problems can undermine sexuality in subtle ways. People with MS who have developed difficulties with short-term memory or concentration may drift off during sexual activities in ways that can be disheartening to their partner. Indeed, the partner may be more aware of this MS symptom than the person with MS.

It requires love and patience to bring these issues out in the open and to seek treatment.

Step 2: Talking to your healthcare team

An easy way to begin the conversation with your healthcare team is by requesting regular checkups related to sexual health. Women should request annual breast and pelvic exams and a pap smear, and discuss the appropriate timing for a baseline mammogram and periodic mammograms thereafter. Men should have regular testicular cancer screenings and prostate exams, and discuss whether the prostate-specific antigen (PSA) test is appropriate. Both men and women may want the most current information about birth control and prevention of sexually transmitted diseases. These requests not only protect your general health, they'll also remind your healthcare providers that you are a sexual being, despite the MS diagnosis. You may then find it easier to report personal symptoms and ask questions.

If you are having symptoms that hinder sexual activity, tell your doctor or nurse — or write out a list that you can hand over to your doctor or nurse. Many sexual problems associated with MS can be medically managed, but your healthcare providers aren't likely to focus on your sexual health if you don't ask.

Sometimes partners pull away from sexual activity because they worry about hurting the person with MS. The healthcare team — particularly the occupational or physical therapist — can be a resource in this situation as well, providing reassurance and suggestions for ways to minimize any pain or discomfort for the partner with MS.

You need to take action if you find that your healthcare provider is uncomfortable, disrespectful or dismissive of your sexuality. This attitude affects your total health care so don't hesitate to seek out more supportive professionals. Contact the National MS Society for referrals. Community gay rights organizations may offer additional assistance to people with same sex partners.

Step 3: Identifying treatment strategies

Assessment of sexual function in MS

There is no single site for sexual response in the human nervous system. The nerves that orchestrate it are spread throughout the brain and spinal cord. This wide dissemination means that there are many pathways where MS lesions (scarring, inflammation, or other damage) might disrupt nerve messages

for sexual activities or feelings. Figuring out exactly what is causing the problems you're experiencing may take some detective work and patience. Your neurologist or primary care provider may consult with or refer you to other specialists, including a psychologist, urologist and/or gynecologist. An MS nurse can also be a helpful resource.

Psychologists and other mental health professionals help people clarify and discuss intimate issues. Counseling often helps couples gain perspective on any feelings or attitudes that may be affecting their sexual relationship. Training in communication may be offered to teach couples ways to talk more easily with each other and with the medical team. Society MS Navigators® can provide referrals to mental health professionals who have experience with MS.

Urologists evaluate and treat both bladder and erectile problems for men, while female sexual issues are more often addressed by a gynecologist. Bladder problems can interfere with sexual activity for both men and women. These are manageable problems that shouldn't be neglected. Urologists may also perform the medical tests to evaluate sexual function in men. These might include penile doppler sonography, which looks at blood flow in the penis, and nocturnal penile tumescence, which determines if the usual nocturnal erections are taking place.

Gynecologists can help identify the cause(s) of changes in sexual arousal and sexual responses that women

experience, and recommend strategies for managing changes in vaginal lubrication.

Managing Primary Sexual Problems — Women

The most common problems experienced by women are loss of sex drive, uncomfortable sensory changes in the genitals, vaginal dryness, and loss of or difficulty reaching orgasm.

Loss of sex drive

The sex drive in women is vulnerable on many fronts. Demyelination, fatigue, anxiety, decreased self-esteem and/or depression can all cause loss of desire. Medication is available by prescription to treat low sex drive, called hypoactive sexual desire disorder (HSDD).

However, diminished sexual desire does not make a satisfying sex life impossible for women. Desire is not a necessary precondition. Women can experience sexual pleasure even in the absence of a powerful drive.

In the movies, desire is always sparked in both partners at once. In real life, one partner produces sexual interest in the other through play — teasing, flirting and foreplay. Many couples discover that the loss of intense sex drive simply means more flirting and foreplay.

Sensory changes

Sensory changes like numbness, which sometimes occur in the vaginal area, can make intercourse uncomfortable or

interfere with orgasm. Medications such as phenytoin and carbamazepine may reduce sensory discomfort. Gently rubbing the genital area with a gel cold pack or even a bag of frozen peas can also reduce discomfort.

Increasing stimulation to the genital area can help overcome numbness. In some cases, oral or manual stimulation of the clitoris will be enough to enable a woman to achieve orgasm.

If this is not sufficient, vibrators and other sex toys may provide even greater stimulation. There are many kinds of vibrators available at adult novelty stores and through mail-order catalogs. Some couples may enjoy the small egg-shaped vibrators made to be worn during intercourse. There is also a device called EROS-CTD — consisting of a soft cup to be placed over the clitoris and a palm-sized vacuum pump that draws blood into this tissue, increasing arousal.

Decreased vaginal lubrication

Decreased lubrication makes intercourse uncomfortable. Water-soluble lubricants are an easy solution. Over-the-counter brands such as K-Y Liquid® and Astroglide® are widely available. Many people find liquids last longer and work more effectively than jellies. They can fail when they are used too sparingly (don't skimp — use lots!). Avoid oil-based lubricants like petroleum jelly because they can trap bacteria and cause infections.

Muscle weakness in the vaginal area

Pelvic floor physical therapy, including Kegel exercises, can enhance vaginal lubrication, arousal and satisfaction. To locate these muscles, try to stop the flow of urine as you urinate. Once the muscle is located, contract it a couple of dozen times a day, independent of urination. Except for the test, don't contract during urination as this may cause a pattern of incomplete emptying, leading to infection.

Managing Primary Sexual Problems — Men

The most common problems experienced by men are difficulty or inability to get or hold an erection, decreased genital sensation, rapid ejaculation, and difficulty or inability to ejaculate.

Erectile problems

In some cases, it may be hard to tell what is causing the erectile difficulties. Demyelination and medications may directly affect erectile function. Stress and anxiety produced by living with MS may contribute to or even be the primary cause of erectile dysfunction. Your healthcare provider will try to clarify the source of the problem in order to choose the most appropriate solution. Understanding the mechanics may help you and your partner.

■ **How do erections happen?**

In the presence of sexual stimulation, nerves in the spongy tissue of the penis release the chemical nitric oxide, which stimulates production of something called cyclic GMP. The release of cyclic GMP relaxes the smooth muscle in the penis, compressing the veins. When this happens, blood flows in but cannot get back out, and an erection occurs.

The fear of having difficulty getting or keeping an erection can be so overwhelming that it causes some men to lose interest in sex entirely. This anxiety may even be the sole source of the problem.

■ **Medications can be helpful.**

There are oral medications used to treat erectile problems. They work by targeting an enzyme that is important for keeping the blood in the penis during erections. Although not all of them have been tested in MS, they are thought to be helpful for about 50% of men with MS. Many healthcare providers see them as interchangeable but generally recommend trying them all since individual responses to them may vary. These drugs work by allowing an erection to occur when a man is adequately stimulated; they do not produce an erection in the absence of stimulation.

Before taking any one of these drugs, it's important to take precautions against possible drug interactions and to discuss side effects with a knowledgeable healthcare provider. Men who have heart or blood pressure conditions or who take nitrate-based medications may be especially at risk for problems.

Other medication options include those that are self-injected into the spongy tissue of the penis. Most men report excellent results with this relatively painless injection that produces an erection without any stimulation being necessary.

■ **Other options are also available.**

The vacuum tube and band device can be an effective alternative to medications. It consists of a plastic tube with a pump and band for the base of the penis. The tube fits over the penis. The hand pump produces vacuum pressure, and the band constricts the veins. This makes the penis fill up with blood, producing an erection. The tube is then removed. Because of its effectiveness and availability, the vacuum tube and band are widely used by men with MS.

The tube and band device can be purchased in specialty shops and through mail-order and Internet catalogs, some of which are listed in the Resource section of this booklet. Catalogs and specialty stores also sell rubber rings meant to be worn at the base of the penis. These rings reduce blood flow out of the penis and can help to maintain erections. It is important to get instruction on using such devices from a urologist or other medical professional to prevent damage to the penis. The vacuum tube and band may also be prescribed by healthcare providers, including urologists.

Several types of penile prostheses are also available for men who aren't successful with the medications or tube and band device. While these have been used very successfully by many men, they require a surgical procedure that brings with it some risk of infection.

Decreased genital sensation

Sensory changes in the genital area may impair pleasure or interfere with ejaculation. Manual and/or oral stimulation may provide enough extra sensory input for erection and orgasm.

Ejaculation problems

Some men with MS may be unable to ejaculate. Others may experience what is known as a “retrograde” or backward ejaculation, in which the ejaculate travels back up into the body. Although this problem is not harmful in any way, it can interfere with efforts to conceive a child. Men who are unable to ejaculate can be given medication or other treatment to stimulate the process.

Addressing Problems Experienced by Men and Women

A variety of strategies are available for managing these primary sexual problems that are common to women and men:

Achieving orgasm

People tend to think of orgasm as the ultimate goal of sex, but this doesn't have to be true. In other words, sex can make people feel good, even when it doesn't lead to orgasm. If achieving orgasm becomes difficult or impossible — either temporarily or permanently — sexual activity can still be pleasurable. And the temporary or even permanent loss of orgasm does not invalidate a man or woman's need

for intimacy and sexuality. Physical intimacy produces emotional intimacy that deeply affects people's physical and emotional well-being.

Despite the tremendous emphasis on intercourse, and orgasm and ejaculation as the “goals” of sexual activity, most people experience great physical and mental arousal from the activities we call foreplay. This is an unfortunate name, because it assumes that these activities are a prelude to “real sex” and not a satisfying form of sexual gratification in themselves.

Making love does not necessarily mean having intercourse. And having intercourse is not the only way to experience sexual pleasure. People who hold themselves to a standard of performance that must begin with intercourse and end in orgasm are going to find less satisfaction than people who are willing to explore and experiment with different sexual activities. This is true for everyone, not just people who live with MS.

Redefining sexuality

Men and women with MS and their partners may want to redefine sexuality for themselves. This may mean putting more emphasis on forms of touching that provide warmth: cuddling, caressing, and massage, for example. Some may need to explore sexual activities that require less mobility. Oral and manual stimulation of the clitoris, penis and many other parts of the female and male body can be highly

satisfying alternatives to “traditional” intercourse. And couples may want to remind themselves just how pleasurable “making out” can be. Kissing is one of those sexual activities that adults tend to rush through in pursuit of an orgasm.

Self-stimulation is an area heavily colored by cultural values and expectations. Some religious groups consider it unacceptable. If that is true for you, please skip the next paragraph.

Many people are uncomfortable with the idea of masturbation; they think of it as a substitute for sex or something that “other people do.” The fact is, most sex experts today say that solo sexual activities help people to redefine and renegotiate their sexuality. If sex is not just orgasm, then sex is not just something that only happens between two people. Self-stimulation reminds us that we do need not be dependent on another person for pleasure and release. In cases where the effects of MS make solo sexuality difficult, the strain and discomfort may be reduced by experimenting with vibrators and other sexual aids.

Rediscovering one’s body through body mapping

Living with a chronic illness makes people very aware of their bodies — the ways it works and the ways it doesn’t. Often this intense awareness makes the body seem strange and unfamiliar. And certain MS symptoms cause the body to respond very differently than it once did. Making peace with this new condition means taking the time to investigate and explore it.

Body mapping is a simple exercise in self-exploration. The

idea is to map out personal sensations by touching yourself from head to toe. What makes your body feel pleasure? Discomfort? Relaxation? Mapping will help identify areas of change, numbness, and discomfort. It will also help locate areas and ways of touching them that produce pleasure.

For this exercise to be successful, it is important to adopt an attitude of open exploration. In a comfortable, secure setting, spend 15 minutes gently touching all the parts of your body that you can reach. Repeat the exercise regularly — several times a week. Linger on the pleasure areas, but don't try to achieve an orgasm. The purpose of body mapping is to get to know your body. Pursuit of an orgasm may interfere with this exploration.

More advanced body mapping exercises include both partners. Exploring each other through touch can help deepen intimacy and enhance sexuality. In some cases, this explorative touching may make verbal communication between partners easier.

Managing Secondary Sexual Problems

Many sexual problems produced by MS symptoms or MS treatments can be managed with the help of your healthcare team.

- Pain can be controlled with medications.
- Spasticity can be reduced with medication, cold packs, and stretching or massage.
- Fatigue can be alleviated through energy management and, in some cases, with medication. Making love at times when the

partner with MS is most energetic (usually the morning) will also help.

- Alternative sexual positioning can help with both spasticity and weakness. Using pillows for support or trying the side positions can relieve discomfort.
- Catheters can be secured during sex. Your doctor or nurse can show you the best way.
- Medication side effects may be minimized by taking medications at a different time of day or by changing the timing of sexual activity. You might also consult your doctor about switching to medications with fewer sexual side effects.

Addressing Tertiary Problems

Tweaking one's feelings or attitudes is never easy — but that is the key to dealing with these sexual issues.

Feeling sexy

Being sexy has a lot to do with feeling sexy. A person can decide to feel good. To start, take care of your body through good healthy food, relaxation and enjoyable exercise. Make time to do things that are special. Spend some time on your clothing and hair. Dress has a huge impact on self image. Select clothing that makes you feel comfortable and attractive.

Thinking sexy

What things are sexually exciting to you? What things are turn-offs? What thoughts interfere with or suppress your sexuality? Self-awareness is an important part of maintaining sexuality in your life, especially if MS has

dampened desire. Thinking more positively will help to restore enthusiasm.

Enhancing romance

When everyday activities take on an aura of the erotic, that's romance. Find ways to transform the everyday into the romantic, for there, intimacy thrives. Dine by firelight, take a bath by candlelight, watch the sun set or the moon rise, hold hands, flirt.

Most important of all, don't give up the pleasures of physical and emotional intimacy. Do give up the niggling worry that sex is not a fit subject for conversation. Talk about it with your partner and your doctors and nurses. It's worth it.

Caregiving and Sexuality

How does one shift from being a caregiver to a lover? In relationships where a partner provides a lot of caregiving, this can be difficult. It is important for the partner to maintain some regular personal time away from caregiving duties because that helps prevent feelings of resentment. It may also be important for the couple to create new rituals and new sexual signals that separate caregiving activities from sex and romance. Talking together about the old signals and rituals may help a couple begin creating new ones.

Living well with MS — and establishing or maintaining healthy intimate relations — requires a great deal from everyone

involved. The Society wants to be an ally, helping people to learn for themselves and to find trustworthy help — from urologists, psychologists, and other healthcare specialists to self-help groups and educational programs. You can connect to the Society by dialing 1-800-344-4867. The following resources may also be of help.

Resources

Books

These titles may be available from the publisher or online booksellers.

Multiple Sclerosis: A Self-Care Guide to Wellness, edited by Nancy Holland, EdD, RN, and June Halper, MSCN, ANP, FAAN. Demos Health (2nd ed.), 2005. 274 pp.

Managing the Symptoms of Multiple Sclerosis, by Randall T. Schapiro, M.D. Demos Health (6th ed.), 2014, 214 pp.

Multiple Sclerosis: The Questions You Have: The Answers You Need, edited by Rosalind C. Kalb, Ph.D. Demos Health (5th ed.), 2012, 426pp.

Multiple Sclerosis for Dummies, Rosalind Kalb PND, Barbara Giesser, MD, Kathleen Costello, ANP-BC (2nd ed.), 2012, 360 pp.

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities, by Ken Kroll and Erica Levy Klein, No Limits Communications. 2001. 218 pp.

The Joy of Solo Sex, by Dr. Harold Litten. Focuses mainly on men. 1996. 193 pp.

Sex for One: The Joy of Self Loving, by Betty Dodson. Focuses mainly on women. 1995. 208 pp.

Society Online Programs

The Society hosts unique and featured wellness education programs throughout the country. Programs focus on connecting people with MS while providing information and wellness opportunities. Program content and objectives vary from location to location, but all have demonstrated impact, provide an exceptional experience for people with MS to connect, learn and make improved lifestyle decisions. Learn more on what's upcoming in your community at nationalMSSociety.org/calendar.

Research help

Sexuality Information and Education Council of the United States (SIECUS) provides a bibliography of print and audiovisual materials related to sexuality and disability. Tel: 202-265-2405. Email: info@siecus.org. Website: siecus.org.

Counseling

American Association of Sexuality Educators, Counselors, and Therapists (AASECT) provides a list of certified sex therapists and counselors in your area. Tel: 202-449-1099. Email: info@aasect.org. Website: aasect.org.

The Marriage and Family Health Center offers sexuality education and therapy programs. Website: passionatemarriage.com

Catalogs

Lawrence Research Group. A catalog of sexual aids, books, resources, and information. They also have a small catalog that targets those with disabilities.

Write: 731 Pilot Rd., Las Vegas, NV 89118.

Tel: 800-242-2823. Email: info@xandria.com.

Sinclair Institute provides a catalog of adult sex education videos. Website: sinclairinstitute.com

Good Vibrations offers online information, sexual aids for purchase, blogs and educational events. Website: goodvibes.com

Websites

sexualhealth.com

The Sexual Health Network's Web page has information on sexuality for those with disabilities and illnesses. It also provides links to other resources and offers live broadcasts. There is an archive of mainly educational books and videos. Care advisors answer questions and offer advice. Tel: 1-855-739-4325.

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The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your healthcare provider.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at [nationalMSsociety.org](https://www.nationalmssociety.org) or 1-800-344-4867.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit [nationalMSsociety.org/brochures](https://www.nationalmssociety.org/brochures) to download them, or contact a MS Navigator[®] at 1-800-344-4867 to have copies mailed to you.

Some of our popular pamphlets include:

- Controlling Bladder Problems in Multiple Sclerosis
- Managing MS Through Rehabilitation
- Exercise as Part of Everyday Life
- Taming Stress in Multiple Sclerosis

**TOGETHER WE ARE STRONGER.
TOGETHER WE WILL CHANGE THE
WORLD FOR PEOPLE WITH MS.**



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