

Sexuality and Multiple Sclerosis

by Michael Barrett, Ph.D.





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The Multiple Sclerosis Society of Canada is pleased to be a source of information about multiple sclerosis. The information in this publication is based on professional advice and expert opinion, but does not represent therapeutic recommendations or prescription. For specific information and advice, please consult your personal physician.

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Preface

I hope this version of Sexuality and Multiple Sclerosis will give people with MS and their partners a blend of information, encouragement and reassurance about some of the possible sexual and relationship implications of MS. My goal is a balanced treatment of the issues most frequently raised by women and men with MS, and their partners, presented with optimism and a touch of humour.

I realize that much of what I say may not exactly fit your personal situation and, indeed, some of it may sound too simplistic, particularly when it comes from someone who doesn't have multiple sclerosis and can never really “experience” what it might be like for you. I have, therefore, tried to include firsthand examples and insights from the experiences of people with MS – single, married, separated, divorced, young, older, heterosexual, gay, and lesbian – and to draw widely from the literature on sexuality and disability.

Since the booklet addresses sexual issues that people with MS **might** encounter in a lifetime, it may be a little overwhelming to encounter all of them in one reading, particularly if the diagnosis of your own or your partner's MS is recent. You may experience an overload of what appear to be potential “problem” areas. Clearly, such issues are a possibility in the lives of everyone, not just people affected by MS. But the downside need not dominate your sexuality. Here's how a woman, who is realistically aware of the occasional guilt,



anger and fatigue that both she and her partner feel around his MS, makes that point:

“If circumstances hadn't forced us to develop our sexual relationship, we might never have discovered the depth and variety of feelings and experiences that are now part of our entire life, not just our sex life.”

I want to sustain that positive message throughout this booklet.

Sex and Sexuality

During a routine physical check-up, Joanne's new doctor asked, “Have you noticed any changes in your sex life as a result of MS?”. Although she felt comfortable talking about sex and had enjoyed her sexual relationship with Bill both before and after their marriage, she was a little taken aback by the question. Her attempt at a non-committal reply, “Well, we've had our ups and downs”, made them both laugh at the double meaning but didn't lead to further discussion. Thinking about it later she realized that a fair bit had changed since her diagnosis five years ago. She and her husband made love less often now, partly because she felt so tired, but also because neither of them seemed as inclined to get things started. They had always incorporated a lot of kissing and manual stimulation into their sex play so her recent need for more direct stimulation to reach orgasm hadn't required a great adjustment to date. She did feel apprehensive about bladder “accidents” and suspected that this concern, along with changes in her genital sensation, balance and energy level, had made her less responsive. Bill was understanding

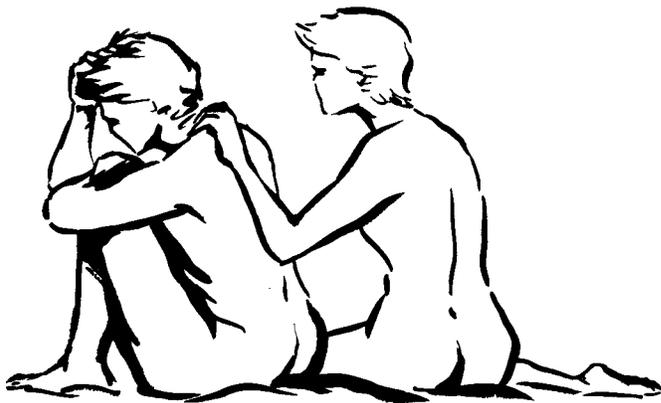
but she couldn't help thinking that he must be turned off by her condition. She was certainly having to work harder to feel good about herself in the face of these changes and particularly because of the mood swings and fatigue she was experiencing. In retrospect, she wondered whether her doctor was asking about the effect of these physical changes on her sexual response or about the feelings surrounding her sexuality. She also wondered whether other women, and men, with MS had similar experiences and how they coped.

The issues facing Joanne involve many different aspects of her “sexuality”, a term that encompasses physical sexual responses (including the capacity to experience sexual excitement and orgasm), fertility and potential parenthood, her perception of her own appearance and attractiveness to herself and her partner (or to potential partners were she not in a relationship), her ability to engage in sexual activity (affected by fatigue, balance, spasticity, etc.), her communication and relationship with her partner (affected by mood changes), her ability to carry on with day-to-day life activities, and her sense of integration, affirmation, and acceptance in the larger network of family, friends, and society. Linked to all of these are Joanne's self-image and self-esteem, the intangible dimensions of sexuality that arise as byproducts of our feelings about ourselves and the reactions of others to us.

Dr. George Szasz, a therapist and researcher at the University of British Columbia, notes that changes in self-esteem and self-image that sometimes



accompany disabling conditions are often the result of alterations in specific aspects of sexual and social life. Our feelings about ourselves are shaped by what we think we should be able to do and by how others react to us. Will she still find me attractive? Can I be a good lover? Why does it take me so long to get turned on? Will my erection last? Can I have an orgasm? How can I have a sex life when I'm always so tired? Will my partner continue to love me? What if I lose bladder control during sex? How much should I tell a potential partner and when? Can I get pregnant? or father a child? Won't I make my partner feel insecure by suggesting changes to our sexual "routine"? How do I get interested in sex when I'm dealing with everything else about having MS? How can I get people to see me as a sexual person and not only as someone with a disabling condition?



Since sex in our society is strongly linked to self-esteem, our "performance" in these physical and partnership spheres of sexual life can have quite direct effects on self-image. Being able to communicate about such topics with partners or potential partners is one way of getting to the broader and deeper issues of sexuality that involve self-

acceptance, trust and love. Those who have no particular wish to become involved in a sexual relationship may nevertheless have genuine concerns about such issues and about the way they are sometimes perceived and stereotyped because they have MS. In the next three sections, I'll consider changes in sexual functioning and relationships that sometimes occur with MS, possible explanations for the changes, and strategies for communicating about them.

Sexual Changes Experienced by People with MS

It is common for people adjusting to the uncertainties of MS to experience a decline in their sexual interest, frequency and enjoyment. These effects are assumed to arise either **directly** as a consequence of the condition (e.g. functional effects on sensation, movement, etc.), **indirectly** as a result of the psychological and social stress and distraction accompanying any major life change, or **interactively**, as a combination of both (Barrett, 1984). Not surprisingly, partners are also affected since they too may experience the understandable anger, guilt, frustration and depression about their changed situation. What may be surprising is the extent to which self-defeating attitudes and assumptions about sex in general, and about sexual "performance" and sex roles in particular, can magnify whatever direct effects MS might have on sexual desire, arousal, orgasm or activity.

What kinds of changes in sexual functioning do people with MS encounter? George Szasz and colleagues assessed 73 men and women with MS on



a sexual functioning scale (SFS) to determine what proportion had experienced reduction or cessation of sexual activity (Szasz et al, 1984a). Half the sample was under 40, 64 percent were female, 62 percent married, 38 percent single, divorced, widowed or separated, and half experienced onset of MS less than 10 years ago. A total of 55 percent said they were as sexually active as before MS and/or that they weren't experiencing sexual problems such as changes in previous genital sensations, erections and ejaculation in men, and vaginal lubrication and orgasm in women". The remainder were either less active and/or experiencing problems or they were sexually inactive (for weeks, months or years) and over half of this group was concerned about the situation and wanted to "regain the previous pattern and functional ability".

Among those who said they were concerned, the most common complaints were: "cannot satisfy my partner", "don't feel like sex", "cannot satisfy myself", "cannot be like a man", "partner doesn't feel like sex" (Szasz et al, 1984a,b). Many of the "traditional" sexual problems described by people with MS are also found in the general population and regardless of their cause, we are likely to have feelings about them. This means that looking for a "physical" explanation for a particular problem (e.g. lack of erection, lack of orgasm) should not lead us to discount the "psychological" factors involved. Nor should we exclude the social factors that limit the sexual rights and opportunities of people with physically disabling conditions. While I am tempted to begin with the physical aspects of sexuality and

MS, since they are often of immediate interest to those experiencing changes in their sexual response, I think the social dimension of sex is so important that it should provide the context in which the functional questions are addressed. And since, many of the examples in the booklet may appear to be aimed more at couples or those already in long-term sexual relationships, I will begin with those who are not.

Single People and MS

The term "single" used to imply unmarried, but it now increasingly means not in a couple relationship. Society seems geared to couples and to the idea that you are either part of one or aspire to be. Advertising is aimed at selling you products that will enhance your potential to attract partners. Since MS is usually diagnosed between the ages of 20 and 40, many of you may have been in relationships that ended in separation, divorce, etc. If you want to establish new relationships or sustain ones that are beginning, a number of factors linked to MS may concern you.

Many of the changes in physical functioning mentioned above and described in more detail below will require both logistical and attitudinal adjustment. If you are in a wheelchair or have difficulty with balance and mobility, able-bodied people may be unsure how to react or be apprehensive about developing intimate relationships. You may fear rejection should you make an approach or show you are attracted to someone. You may have gotten out of practice in the verbal communication and cuing that makes people interested in you and that conveys your interest in them.



Your living situation may restrict opportunities for privacy or for meeting people. This is particularly true in institutional settings although some are developing sexuality committees, privacy rooms, and other policies to support the sexual rights of people with disabilities.

If you require attendant care, this can be a barrier to sexual expression unless you can communicate your wishes and needs clearly and confidently. This is not easy if you are shy, or want to keep your sex life confidential, or if you are having trouble seeing yourself as a sexual person worthy of relationships and pleasure. If your partner must also provide attendant assistance you may wonder when and how to bring this up. Similarly, if you have encountered changes in your sexual responses in previous encounters, you may be apprehensive about trying again or uncertain about bringing the subject up in advance.

Encompassing these and many other such issues you may have experienced are some common themes. These include: body image and self-esteem, sex role expectations, false assumptions about disability, and the need for effective communication, particularly between men and women who have been socialized in different ways and may therefore differ in their experience and interpretation of sexuality.

For example, Janet, 39, has had MS for 10 years and was divorced four years ago following a period of criticism that really deflated her ego. She had always valued her appearance and athleticism as an aspect of her sexuality but her outward demeanour belied a wish for intimacy

and security in her marriage. Since the divorce she has had two relationships, but both men acted as if they were only interested in sex. She also sensed that they felt they were doing her a favour as if she should be grateful for their attention. She is having difficulty finding partners who will relate to her emotionally and intellectually as well as physically. She has a satisfying life with work and friends and is beginning to wonder whether the kind of relationship she wants is realistic or worth the trouble.

Bob, 47, has tried to play the field sexually although his MS symptoms, particularly balance problems and fatigue, are making all aspects of his life more difficult. He is now realizing that the dominant, assertive, “in-charge” script he brought previously to his work and social life, is in conflict with the growing insecurity he feels about his sexual response and “performance”. “What with concerns about AIDS and other sexually transmitted diseases and the altering relationships between women and men in society,” Bob says, “the game has really changed.”

Joseph Nowinski (1984) points out that recognizing the problems created by male sexual socialization does not mean that Bob has to reject all “traditional” dimensions of his masculinity. The problem comes from “our tendency to restrict men to one script and women to another as the exclusive means for expressing their sexuality”. Problems frequently come for men, he says, “when they try to meet excessive expectations, to live up to stereotypes that deny their sensitivities, and to limit the expression of their sexuality to the machismo role.”



Interestingly, he notes, “we teach women to expect the same things from men that men expect from themselves.”

If you are single, here are some questions you may have asked yourself. What am I looking for in a relationship and what will I bring to it? Do I want someone who will care for me and look after my physical needs or do I hope for more interdependence? Am I looking for companionship? Am I worried about loneliness and old age? Do I feel optimistic or despondent about my sexual possibilities and about my chances for a long-term relationship? Would I really be happier with some good friendships and less intense involvement with one partner?

MS Society chapters or clinics may have social groups, or organized meetings and discussions in which you could explore these issues with others who have “been there”. This kind of exchange can often be prompted by an invited speaker, film or some other planned activity that gives participants “permission” to talk about this area. When I speak to such gatherings, I meet people who have a wealth of personal experience and insight that they are willing to share in the right circumstances. Interestingly, some people with MS may avoid such groups simply because they “don’t want to be labelled by being in a group of people with disabilities”. These feelings too are worth exploring in the broader context of sexual and relationship expectations.

Gay Men and Lesbian Women With MS

In the second edition of this booklet (1982), I wrote: The “presumption of heterosexuality” that prevails in our society also pervades the literature on sexuality and disability. It will therefore be difficult for those of you who have MS and are gay to find anything written about the sexual problems and needs of gay disabled men and women.”

Alas, the situation is only slightly improved today. Although there is a rich body of literature about gay relationships, I have found little on lesbian and gay disabled people in general and nothing specifically about gay people with MS. While you probably share many of the experiences described here with other men and women who have MS, I think a gay person with MS can encounter situations particular to being “a minority within a minority” (Stewart, 1979). For example, it may not be as easy for you to find health care professionals who are both knowledgeable about MS and insightful in dealing with gay individuals and couples. MS societies may be similarly inexperienced and less able to put you in touch with a network of peers. A recently formed organization, EDGE, (Education in a Disabled, Gay Environment, Box 305, Village Station, New York, N.Y. 10014) is one of the few I know that focuses specifically on gay people with disabilities.

Beth, 31, came out to her parents several years ago shortly before she was diagnosed with MS. Her parents have had difficulty accepting the idea that she is gay but have been supportive in helping her adjust to the physical impact



that MS is now having on her work and social life. Her sexual experiences began later than her peers, and she was just beginning to fully enjoy her sexuality when the blurred vision, loss of balance and numbness in her legs began. She has recently found it difficult to let go sexually and to experience orgasm. She is not sure whether it is the medications, that sometimes leave her groggy, the occasional muscle spasms that make her feel unattractive, the worry that her partners may be put off by her slow response, or whether something directly related to MS is the explanation. It makes her angry when she catches herself feeling inadequate or self-critical as if she is somehow responsible for having MS.

Yvonne Duffy's (1981) book, *All things are possible*, includes a chapter on the feelings and experiences of lesbian women with disabilities. While some of their quotes expressed negative experiences related to family rejection of their sexual orientation or shyness at approaching possible partners because of concerns about their disability, others stressed feelings of adequacy, satisfaction and a sense of strength and self-acceptance that comes from intimate relationships that seem right for you. A book recommended by Duffy (*Sapphisty: The Book of Lesbian Sexuality* by P. Califia, 1980) is one of the few I know of that includes discussion of sexuality for disabled lesbian women.

Ted's MS recently reached a point where he could not care for himself in his apartment, and his lover Phil was unable to miss as much work as would be needed to care for him. The chronic care

setting where Ted has been for the last four months is not geared to providing either the social life that Ted thrived on nor the privacy that he and Phil repeatedly requested. Ted was sexually frustrated by this situation, but he also missed the physical closeness and caressing. Their touching caused poorly disguised discomfort among some residents and staff. Ted also had questions about the changes in his sexual responses over the past year, particularly the reduced sensitivity to anal stimulation which had always been highly pleasurable for him. He was not sure who to ask about this or what kind of reaction he would get if he did. He knew he was not the only person in the facility with such concerns.

Lack of privacy and reduced opportunity for intimacy and touch are common experiences for people living in institutional settings. I think the attitudinal and administrative barriers that stand in the way of sexual rights for people with physical disabilities are even greater for gay and lesbian individuals and couples. However, I have seen enough examples of genuine caring among health care professionals in and out of institutions, to make me guardedly optimistic that this goodwill holds the potential for real improvements in both attitudes and policy.

In addition to the kinds of issues highlighted in the previous anecdote, gay men with MS and their families and friends may face the personal and social implications of HIV/AIDS. This can include grief at the loss of loved ones, concern for one's own well-being, and anger at the stifling effect of



discriminatory attitudes. While all of society is affected by HIV/AIDS, I think gay people and people with disabilities share a particular awareness of the negative impact that such attitudes can have on all aspects of life including self-esteem. The British Columbia Coalition for the Disabled has recently established an AIDS and Disability Project to deal specifically with the implications of HIV infection and AIDS for people with physical disabilities (Sands, 1988).

Sexual Response Changes in Men With MS

Among men with MS, anywhere from 26 to 75 percent have been reported to have erectile difficulties depending on their age, duration of MS, and severity of MS symptoms (Vas, 1969; Lilius et al, 1976; Goldstein et al, 1982; Smith, 1976; Minderhoud et al, 1984; Valleroy and Kraft, 1984). Concerns about rapid ejaculation (premature ejaculation) also occur as do dysfunctions of orgasm and ejaculation either in association with erectile problems or, as we will see later, in their absence (see Schover et al, 1988).

Recently, Stenager et al (1990) reported either less frequent sexual activity and/or the presence of some sexual problems in 33 of 52 Swedish men with MS. Complaints included erectile dysfunction, premature ejaculation, changed sensation in the penis, reduced sexual desire and orgasmic dysfunction. Interestingly, only 45 percent of those who experienced changes in sexual activity or response claimed to be concerned about the change.

I think it is understood that the emphasis on erection and orgasm that permeates the literature on male sexuality and disability reflects not just an interest in “technical” problems that may have medical explanations and treatments. It indicates, as well, the symbolic meanings we attach to manhood in our society. Here’s how D.H. Hall (a pseudonym) quoted by Robin Frames (1989) describes it:

“I was deeply ashamed and embarrassed about being impotent. It related to my manhood – not just being macho or who can beat up who or being gung-ho on sports – but about my being a male. It goes very deeply and is very hard to admit to yourself, let alone other people...You do not make small talk over the fence with a neighbour and say, “Oh, did I tell you I was impotent?...”

Another man writing about his difficulty in reaching erection and orgasm wrote:

“We go to bed now knowing that perhaps it will work but probably it will not. A feeling of alienation has entered my consciousness toward this act, which can be such an incredibly beautiful experience. I know of ways whereby my sexual feelings might be further heightened, but I rarely discuss these techniques with my wife. She always takes my failure as her failure...My wife’s anxiety concerning my situation makes my awareness of the frustration all the more acute, and so we are losing our spontaneity and exuberance...” (Pulton, 1975).



Sexual Response Changes in Women With MS

There is much less research on the specific effects of MS on sexual functioning in women. In a group of 25 Swedish women with MS (ages 20-42, disability level 1-2 on a 6 point scale), Lundberg (1978) found that 52 percent had some kind sexual problem, usually appearing rather abruptly, that they had not experienced before the start of their illness. Predominant among these were insufficient vaginal lubrication (in two-thirds of those who reported problems), changes in genital sensation that sometimes made clitoral or vaginal stimulation highly uncomfortable, and difficulty in achieving orgasm. All but one woman continued to have sexual intercourse although not as often as before. Based on four separate studies, Schover and Jensen (1988) suggest that about one-third to one-half of women with MS may have some kind of problem with orgasm (Lilius et al, 1976; Lundberg, 1978; Minderhoud et al, 1984; Valleroy and Kraft, 1984).

In a recent study by Stenager et al (1990) it was found that 32 of 65 Swedish women with MS reported either less frequent sexual activity and/or presence of some sexual problem. However, only 12 percent of the 32 expressed concern about the changes which included changed sensation in the genital region, reduced vaginal lubrication and reduced sexual desire.

Women with neurological conditions causing symptoms similar to those in MS describe the same kinds of direct effects

on sexual response (Bregman, 1978). This can be explained, at least in part, by the effect of MS on altered nerve function (explained below) but the contribution of indirect effects is also important. For example, Szasz et al (1984b) describe the experience of a 32 year old woman who had been orgasmic with vibrator stimulation prior to her diagnosis with MS two years before. While her condition was now stable, she retained some difficulty with coordination, residual spasticity, slight effects on her vision, and insecurity about bowel control. She said she had lost her sexual interest for a while after diagnosis and stopped using the vibrator for over a year. Upon resuming use of the vibrator she found she was able to become aroused but not to have orgasm. She became discouraged, thinking the MS was blocking her response. As she described it, "I was mad at my body - why doesn't it work?" After brief counselling and homework "exercises" in which she explored her sexual responsiveness, she began having orgasms again. Neurological effects from her MS may well have contributed to her difficulty in reaching orgasm, but it would not be surprising if anger, anxiety, depression or her sense of "failure" at not responding were also contributing factors along with the effects of MS.

Many of the sexual response changes experienced by people with MS have this mixed input from physical, psychological and social factors. Even if the initial "problem" appears to you to be a direct effect of MS, your feelings about it (or a partner's reaction) are part of the memory you take into your subsequent experiences. If the neurological effects of



MS contribute to a temporary lack of erection, vaginal lubrication or orgasm, you may think about this next time. Those thoughts can generate anxiety (performance expectation) which blocks arousal or they can simply distract you from experiencing otherwise pleasurable stimulation. If effects of MS on nerve function are present, the added effects of distraction and anxiety compound the situation. One step in understanding and then communicating about such issues is to recognize the interaction of physical, psychological and social factors in MS.

Sexual Response Cycle and MS

Although what people do to express their sexual desires varies greatly, the bodily changes and processes associated with sexual response are more predictable. Drawing from the earlier work of Masters and Johnson (1966), and more recently, Helen Singer Kaplan (1979, 1983) and others, many researchers now think of the sexual response cycle in four phases: desire; arousal; orgasm; resolution (return to the unaroused state).

Desire Phase

Consider the statements “I’ve lost my interest in sex”, or “I can’t get in the mood”, or “I think about sex all the time but I can’t do anything about it”, or “I wish I could feel the way I used to but I just don’t seem to get turned on anymore”. People can experience sexual desire as anything from a consuming, passionate, eagerness for sexual contact and arousal to a mild inclination to “give it a try and see what happens”. Others experience desire more as a wish for physical closeness, intimacy and connectedness that may or may not lead

to genital excitement. We assume the presence of desire by what people do (private fantasies and thoughts about sex, initiating or responding to sexual overtures, masturbation, reading erotic novels, etc), but of course people can “give in” to a partner’s wishes without feeling desire themselves.

Inhibited sexual desire (ISD) is one of the most common sexual “problems” seen by therapists treating the general population. When this has a direct physical basis, it is usually due to clinical depression, brain injuries, decreased testosterone levels, elevated prolactin levels, side-effect of medication, or other such factors. The effects of MS on sexual desire are probably indirect, arising as a result of depression, fatigue, etc., rather than as a direct consequence of nerve damage to brain centres involved in sexual fantasy or to altered sex hormone production. Since desire involves elements of memory and conceptualization, it is possible that neurological changes that affect cognitive function (see below) may also influence sexual desire. To my knowledge, this linkage has not been well studied in people with MS although the effect of cognitive changes in MS is known (Stenager et al, 1989a, b).

Similarly, I have seen no studies on partners of people with MS to determine how their sexual desire and responsiveness are affected. Intuitively, one suspects that sexual interest might wane in the face of fatigue arising from taking on previously shared tasks, or of guilt over unexpressed feelings, or of depression as a result of both. I assume that other aspects of sexual response discussed below in the context of MS,



could also be affected in partners in the same way that anyone would be affected given similar interpersonal and social circumstances. Furthermore, partners may downplay any changes they experience for fear of seeming selfish, complaining or threatening to a loved one whose ego may be fragile. However, we know too little about what actually happens for partners of people with MS.

Arousal Phase

“Sometimes we go to bed and I’m feeling sexy but it seems like my wife could stimulate my penis forever and it wouldn’t get erect.”

“I look at erotic magazines or create fantasies in my mind to increase my mental excitement. That doesn’t always produce genital arousal the way it used to but I’m learning to relax and not pay so much attention to how my penis is doing.”

“I find that my nipples are extra sensitive and sometimes certain areas around my clitoris so I’ve learned to stimulate myself there and to show my partner where it feels best.”

“We had a period of time where he was trying so hard to give me an orgasm that it started to feel like work. The harder we tried the less arousing it was for both of us. I wasn’t sure whether my lack of response was due to the MS or due to my worrying beforehand whether it would work this time or not.”

It may not sound very erotic, but the changes your body goes through when you are becoming sexually aroused involve two processes: **vasocongestion**

(blood flows into an area faster than it flows out) and **myotonia** (build up of muscle tension). Both are controlled by nerve impulses, either those from the brain down the spinal cord to the genitals (and other areas), or those carried from erogenous zones on the body (genitals, nipples, skin) into the spinal cord and to the brain. I will focus initially on vaginal lubrication and penile erection to describe the possible effects that MS can have on sexual arousal, but I don’t want to lose sight of the fact that all of the body, not just the genitals, is involved. Remember also that there is a person attached to those genitals (both literally and figuratively).

Erection and vaginal lubrication

Some of you may wonder about my linking of erection and vaginal lubrication in this discussion. Lubrication is among the earliest signs of sexual arousal in women and the physiological parallel of erection in men. The two reactions seem to have taken on very different meanings and social significance. When erection is interfered with because of anxiety, distraction, fatigue, nerve damage, or a combination of these, we tend to focus on this as the “problem”. The term “impotence” is often used for this lack of erection although I think the word now carries unwarranted connotations of powerlessness that are both misleading and needlessly stigmatizing. Men who have erectile dysfunctions may nevertheless be sexually active, erotically interested (and interesting) and socially and professionally capable. It’s possible that the term can be rehabilitated through wider public discussion and comfort with the issue, but my inclination is to avoid



using the label “impotent”, in the same way that we have discarded the term “frigid”. Women who don’t experience strong physical sexual arousal or orgasm rightly reject that label which seems to deny them warmth, responsiveness and an agreeable personality.

Although women with MS who report a reduction in their sexual arousal may cite lack of vaginal lubrication as a specific symptom, I think they are more likely to say that they don’t feel excited sexually rather than focusing on “lack of lubrication” as the problem. This may mean a loss or reduction of some of the feelings they usually associate with arousal, for example, sensations in the clitoris, labia, vagina, etc., but it is less focused on a particular organ (as in erectile dysfunction) and more on the whole experience.

Some people with MS are reassured to know that there are “physical” reasons for the changes they may be experiencing in their sexual response. For example, if you know that MS can damage the nerves that control erection or vaginal lubrication and arousal, you may well feel angry or disappointed that you are not responding the way you would wish, but perhaps you will be less likely to say “I’m a failure. It’s all my fault”.

Sexual arousal involves nerve-controlled processes. In penile erection, nerves stimulate blood vessels that go to the spongy tissue of the penis. This causes some inflow vessels to dilate (expand so blood flows in faster) while outflow is lessened. This expands chambers in the body and head of the penis which enlarges and becomes erect.

The same thing happens in vaginal lubrication. Blood flows rapidly into the vessels surrounding the vaginal barrel and the increased pressure forces fluid through the walls of the blood vessels and through the vaginal lining to moisten the surface. Increased blood flow to the clitoris and labia also takes place during the arousal phase causing swelling of the labia and some enlargement of the clitoris. Most of us are not thinking about these bits of physiology while they are happening, (“Darling, you really make me feel vasocongested”), but knowing how the nervous system controls sexual responses can be a good antidote to the performance pressures many of us feel when things go wrong.

Nervous system and sexual arousal

MS involves lesions on the myelin covering of the central nervous system — white matter of the brain and spinal cord. Its effects on sexual response can vary with the location and severity of the damage. Sticking with erection and vaginal lubrication as examples of genital changes during sexual arousal, we know that these can take place **psychogenically** (messages from brain down spinal cord to genitals), **reflexogenically** (messages from genitals to spinal cord and back to genitals), or usually by both routes at the same time. These and other aspects of sexual arousal are controlled mostly by the parasympathetic nervous system, the part of your involuntary (autonomic) nervous system involved in relaxing, recuperative functions. There is also some input from the sympathetic nervous system, (this is the other half of the autonomic system and it plays a major role in orgasm phase), and also from the



sensory part of the central nervous system which carries touch and pressure sensation to the brain from all parts of the body.

In penile erection, for example, touching of the penis or genital area sends impulses along parasympathetic fibres of the pudendal nerve to the lower (sacral) region of the spinal cord (S2-S4, Figure 1). Chemical connections (synapses) between nerves in this region of the cord allow messages to be sent directly back to penile blood vessels along the pelvic nerve thus causing dilation of blood vessels and erection. The same thing happens with touch stimulation of the clitoris, labia, vagina or vulva leading to vaginal lubrication and engorgement of the clitoris and labia.

This **reflexogenic** response doesn't require that the impulses go up the cord to the brain before a response occurs. For example, some men and women with spinal cord injuries above the sacral region, but with the sacral part of the cord intact, may experience these reflex reactions. People with MS might also respond in this way although the nerve damage in MS may occur at various places along the cord, rather than at a specific point as in cord injury. This aspect of MS makes it more difficult to make textbook predictions about the effects of MS on sexual response for any individual (some possible tests are discussed below).

The term reflexogenic is a little misleading because sexual response is not really a reflex like your knee jerk or eye blink reflex but it does convey the idea that you don't have to "will it" to occur.

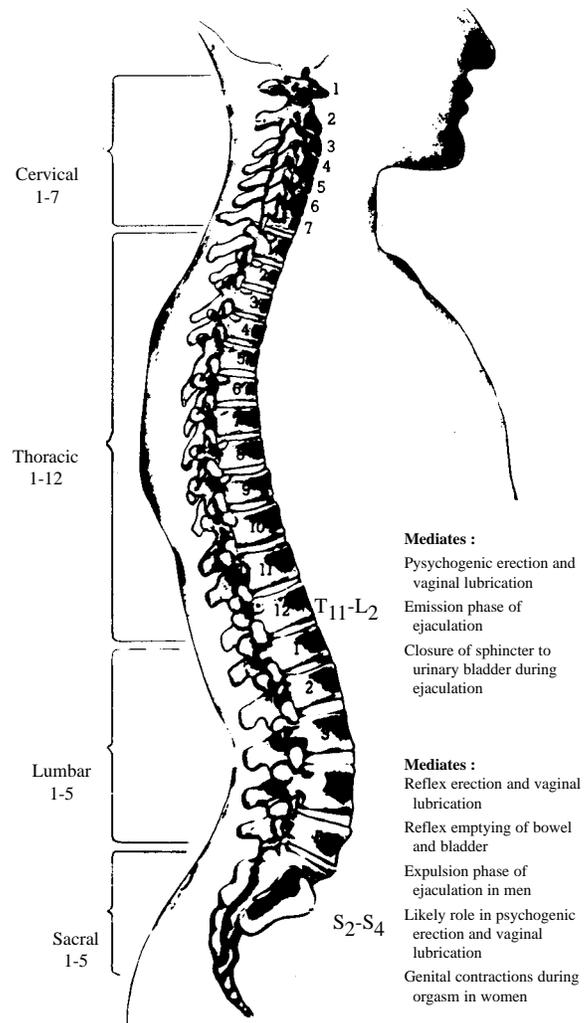


Fig. 1. Regions of the spinal cord showing the two areas involved in genital sexual response and in the control of bowel and bladder function.

When nerves in the spinal cord are intact, impulses arising from genital stimulation travel to the brain where we perceive and interpret the sensations ("feels good", "faster please", "gentler", "not there yet", etc.). These mental perceptions become part of the **psychogenic** component of sexual arousal in which nerve impulses from the brain travel down the spinal cord to the genitals. Their routes of exit are via the hypogastric nerve (part of the sympathetic system) at the junction between thoracic and lumbar regions of the cord (T11-L2, Figure 1) and probably



also the pelvic nerve from the sacral segments (S2-S4) as described above. Both lead to the genital blood vessels controlling erection and lubrication. Any MS-related damage to nerves in these regions of the cord or in their connection to the brain, can have an impact on sexual arousal mechanisms.

The psychogenic mechanism doesn't require prior genital stimulation. Any thoughts or fantasies you find arousing, any sights, smells, tastes, words or touches that have erotic meaning for you, all these can contribute to sexual excitement. Indeed psychogenic responses can happen in the absence of the reflex pathway. For example, people with lower cord injuries in which sacral segments are damaged but thoracic and higher regions are intact, can have psychogenic genital arousal even in the absence of genital sensation. This can also be the case with MS, although the potential for nerve damage at various levels in the spinal cord makes this kind of analysis, as noted above, more complex.

Usually psychogenic and reflex responses occur together and are mutually reinforcing. If one or both of these is reduced as a result of nerve damage from MS, it may take some experimentation to find the kind of stimulation that is most effective. This is not always easy to sort out particularly if we focus on our genital reactions as the only route to sexual enjoyment. In fact, many other parts of the body can be "eroticized" for sexual pleasure. In addition, touching and caressing **without** the expectation of sexual arousal either for the toucher or by the recipient are enriching aspects of

sensual communication that are sometimes neglected. The section on Enhancing Sexual Enjoyment discusses this range of possibilities and suggests ways of reducing the "goal directedness" of sexual interactions.

Effect of "performance anxiety" on sexual arousal

If previous disappointments have left you worrying about being a "good lover" or wondering "will it work this time", it is easy to see how this "performance anxiety" can interfere with sexual excitement. First, these thoughts can intrude on your psychological arousal by distracting you from the feelings and sensations that would otherwise be arousing. Second, such apprehension causes release of adrenalin, your sympathetic nervous system's response to stress. Sympathetic nervous system activation is a natural preparation for "fight or flight" reactions in the face of danger. Adrenalin inhibits the parasympathetic nervous system since blood flow to the muscles rather than the genitals is beneficial if you are in real danger. Since we also release adrenalin in response to anxiety, including anxiety about sexual performance, this "natural" mechanism can interfere with sexual arousal.

Most men at some time or other have experienced this effect of anxiety on erection. It is talked about less in women, but the process probably operates the same way in both sexes. Masters and Johnson call it "spectatoring", the act of watching and perhaps worrying about how you are doing.



When combined with negative thoughts (“Why isn’t anything happening”), this process can delay or block sexual arousal even without the added complication of neurological problems from MS. A partner’s reaction further complicates the picture.

“Jim is aware that his frustration over the unpredictability of his erections is affecting his relationship with Janet. She says they can enjoy themselves without intercourse, but he senses that she is apprehensive about touching his penis because he might interpret this as her putting pressure on him. She does feel this way, in part because of his comment about “flogging a dead horse” during the last of their increasingly infrequent encounters. While they both know that MS can affect his sexual response, they haven’t yet found a way of having sex where erection isn’t in the back of both of their minds.”

“Laura and Gary both noticed that genital caressing wasn’t getting her aroused the way it used to. It seemed to take longer, and she was aware of some discomfort during his prolonged stimulation. Since she had experienced some problems with bladder control, she wasn’t sure whether her apprehension about this might be making her less responsive. Concerned about hurting her and also about whether she was enjoying his stimulation, Gary became watchful of Laura’s face for cues and less spontaneous in his lovemaking. He also needed more verbal feedback from her to let him know how she was feeling. For Laura, his questions became a reminder that she was not responding the way she used to. Both of them know that MS can interfere with her sensations

and bladder control, but they don’t know if that is the explanation in her case. Even if it is, that information alone doesn’t tell them how to adjust to it.”

Orgasm phase

In men, the expulsion of seminal fluid (ejaculation) and the mental sensation of orgasm usually happen at the same time, and we often talk about them interchangeably. They are, however, separate phenomena that can occur independent of each other.

Ejaculation is a two-step process. The first, **emission**, happens just prior to the expulsion of semen and involves rhythmic contractions of muscles in the vas deferens (the duct carrying sperm from the testes), the seminal vesicles and prostate gland (the source of most of the volume of ejaculate). These involuntary contractions are controlled by sympathetic nerve fibres in the hypogastric nerve (T11-L2 region of spinal cord, see Fig. 1) causing release of seminal fluid into the prostatic urethra. This is a prelude to the second phase, **expulsion or ejaculation**, in which contractions of muscles in the penis and groin area (controlled by nerves in the S2-S4 region of the cord, Fig. 1) cause release of the fluid to the outside. At the same time, sympathetic nerves in the T11-12 region contract the neck of the bladder so that seminal fluid is expelled to the outside rather than back into the bladder.

The expulsive contractions of ejaculation have their parallel in the rhythmic muscle contractions in the outer one third of the vagina and in the uterus that happen in female orgasm. Some women release a



spurt of fluid at orgasm which was traditionally assumed to be urine but which may well be orgasmic secretion from Skene's glands located around the urethra. This fluid appears to be "thinner and more slippery as well as having a more intense release" than vaginal lubrication, and to be released more commonly by women who report a sensitive area in their vagina (Grafenberg Spot) which can act as a trigger for orgasm (Davidson et al, 1989). This explanation for this phenomenon is a source of debate in the academic literature on sexual response (Alzate and Hoch, 1986; 1988), but it is of more than theoretical interest to those women with MS who sometimes experience bladder incontinence (see below). The fluid described here is reportedly different from urine and women who release it may find that this is part of their sexual response not an unwanted urinary accident (Belzer, 1981).

With MS and a number of other conditions, it is possible for men to have dry orgasm (no ejaculation), decreased intensity of orgasm, inability to reach orgasm, or ejaculation in the absence of any feeling of orgasm. Dr. Leslie Schover and her colleagues at The Cleveland Clinic Foundation point out that some men with MS who do not have erections might nevertheless reach orgasm with manual, oral or vibrator stimulation if they were aware of this possibility. "Unfortunately", says Schover, "urologists and mental health clinicians overlook orgasm phase dysfunctions when a patient seeks help for an erection problem (Schover et al, 1988).

To my knowledge, there is no comparably detailed literature on specific changes in the orgasmic experience of women with MS.

Communicating About Sex

If intimacy is established through effective communication (Masters et al, 1986), it is a shame that more of us weren't taught the needed skills when we were younger. The sexual issues facing people with MS and their partners (Kalb et al, 1987; Carrera and Kelley, 1979) require effective communication. Talking about sex can be threatening, particularly if we fear that it may lead to rejection, to loss of spontaneity or to increased tension in an already stressed relationship. We may worry that raising a dissatisfaction will seem like a criticism of an already burdened partner.



Common issues people may want, or need, to discuss in their sexual relationships include: frequency and types of sexual activity (e.g. introducing new sexual practices), use of fantasy, desire for more emotional intimacy, desire for less specific role expectations (who initiates, positions), reduced focus



on intercourse and orgasm, more non-sexual touching, more tenderness and gentleness, more assertiveness and passion, not being taken for granted, more open communication about any of the above, and reassurance that you are loved and needed.

People with MS who are not in sexual relationships at present because of lack of interest or opportunity face an added set of communication issues to be discussed later.

Couples coping with MS are often told they must communicate with each other as if the admonition was enough to achieve the goal. This is a message heard by all of us, not just those where a partner has MS. But how do we do it? What if our past attempts have been rebuffed? Or led to argument rather than greater understanding? Or if our relationship isn't so secure that we feel able to bring up sexual concerns. In the absence of magic answers, here are some selected observations from counsellors who deal with couples in which one or both partners has a chronic illness.

Schover and Jensen (1988) identify four "couple skills" that are important in a "well-functioning relationship": allocating roles, respecting each other's boundaries, achieving a good level of communication, and agreeing on relationship rules.

1. **Allocating roles** – In this area the key words appear to be "flexibility" in sharing tasks, "functioning" in ways that avoid parent-child type interactions between partners, and "fostering" opportunities for private adult time

away from the demands of daily routine. Whether your relationship is based on a "complementary" model of male-female gender expectations (he does some things, she does others), or "symmetrical" (we share all tasks equally, e.g. taking turns), or some combination of these, MS may have affected the pattern in ways that can directly and indirectly impinge on your sexual relationship. If you have had a very complementary approach to roles, it may be harder to shift responsibilities. For example, "Bill usually initiated our sexual interactions, but since he developed MS he doesn't do that as much".

MS may also lead one partner to adopt the parent role in the face of the other's chronic condition. Schover and Jensen (1988) give two examples. The assumption by a man that he must "direct his wife's medical care and hold the family together. A decrease in sexual activity may stem from the man's overprotectiveness and his wife's concept of herself as impaired..." or a women's inclination to monitor aspects of her partner's daily living to the extent that they are both less able to perceive him as a lover. Finally, "if one partner scrambles frantically to complete the work of two" say Schover and Jensen, "particularly in couples with young children", adult time may be sacrificed to the detriment of the sexual relationship. One way of identifying such changes in a relationship, they suggest, is for couples to chart their allocation of tasks and of "adult time" before and after diagnosis as the first step in finding mutual solutions. They can do



this on their own or with the support of a counsellor or therapist as their situation warrants.

2. **Respecting Boundaries** – Couples develop a fluctuating balance between intimacy and autonomy, between the need for closeness and the need for independence and privacy. A disability can disrupt this balance by causing you to spend more time together than usual, disrupting shared and individual patterns of recreation, or even exerting “pressure on partners to prove their love by being more affectionate than usual” (Schover and Jensen, 1988).

Having MS makes Derek fearful of losing Gail’s affection. He reacts by becoming quieter, touching less, showing less sexual interest. Gail responds by becoming more attentive than usual, constantly checking his feelings and mood. For both of them, reestablishing comfortable boundaries will require effective communication.

3. **Communication Styles** – While most of us have a variety of communication styles, Schover and Jensen (1988) find that one or two may predominate, particularly in people dealing with the stress of a condition like MS. They identify four different defense mechanisms that can influence communication styles: **withdrawal** (“I can imagine what he’d say if I showed interest in him so I’m not going to risk it”); **denial** (“there’s nothing wrong”); **projection** (“I feel this way so my partner probably does too”); **passive acceptance** (“that’s the way it is, there is nothing I or we can do about it”). With a slightly different twist, these can also be ways of adapting.

Withdrawal – Negative: Jane says, “No man will be attracted to a woman who has my problems with mobility and balance. I don’t bother to go out anymore.” Positive: Jill says, “I’ve got to take some time to get used to myself, then I can think about dating again.”

Passive acceptance – Negative: Bill says, “I can’t get an erection anyway. That’s what happens with MS. What’s the point of having sex.” Positive: Gordon says, “I’d rather have erections but if that’s the way things are right now I’ll just have to find other ways of getting sexual enjoyment.”

Projection – Negative: Judith says, “He broke up with me because of my MS.” Positive: Gloria says, “There were lots of things in the relationship that neither of us were happy about, and MS may have been one factor”.

Denial – Negative: Al says, “I don’t see how drinking less would improve my sex life. I always drank, and it was never a problem before.” Positive: Steve says, “I’m not ready to cut down on my drinking yet. I need the socializing with my friends. If it’s having an effect on my sex life, I’ll deal with it when I feel more secure.”

Schover and Jensen (1988) also identify several “relationship rules” that may help people to communicate more securely about sexual topics in the face of a disabling condition.

1. A basic commitment that the relationship will not be threatened by conflict.



2. We share power equally in the relationship. One of us is not “in charge”.
3. When conflict occurs, we will resolve it.
4. Each person feels accepted unconditionally.
5. The most important time is here and now.
6. It takes some effort to establish and maintain a relationship including a sexual relationship.
7. The fantasy that it should happen “naturally” is just that, a fantasy.

Some Ideas for Communicating About Sexual Concerns

Masters et al (1986) describe three main reasons for lack of clarity in communication about sex. First, we don't always say what we mean for fear of hurting someone we care about. Second, we send mixed messages with a contradiction either in what we say or in our tone of voice or non-verbal signals. Third, we are not specific. The comment “Our sex life seems to be a low priority lately” may raise rather than invite questions (my fault? is she unhappy? is our relationship in trouble? what does he want?).

Here are several suggestions for enhancing clarity in communication about sex (Master et al, 1986; Brenton, 1973).

1. Think through what you want to say and find out from your partner when she or he would be most comfortable talking. Right after an unsatisfying encounter (“instant replay”) may not be the best time for some but OK for others.
2. Be clear about your priorities. Keep it brief with a few points that come from your own feelings (use “I” language) and do not start with criticism or accusation. The statement “You seem in a hurry to have intercourse without thinking about my enjoyment” may be less engaging than “I'd like to spend more time kissing and caressing before we have intercourse”. Therapist Stephen Treat (1987) points out that some “I” messages are really disguised criticisms (“I feel that you don't really care how I feel) while other express genuine vulnerability (“I feel close to you”; “I feel hurt”).
3. Asking for variety in a sexual interaction or for new activities can make us feel insecure (“Perhaps I'll be rejected or considered kinky.”). Don't use persuasion. Don't become accusatory. Remember that a “no” does not mean rejection of you as a person.
4. Don't talk at your partner. Allow a chance to respond. When you do respond, don't ridicule, refuse to discuss it, or make your partner feel guilty for asking.



5. Don't try to talk when you are angry, have had too much to drink, or have too little time or privacy.
6. If you want a different kind of stroking or caressing, actually showing a partner may be easier than describing it in words, then he or she doesn't have to guess.
7. Don't expect perfection. Here's how Masters et al (1986) describe it:

“Intimate relations can stumble if partners expect that sex should always be a memorable, passionate experience. Realize that just as your mood can change, or your physical feelings ebb and flow, so too can sexual experiences range from ecstatic peaks to fizzled-out fiascos. It isn't necessary to analyze what went wrong whenever sex isn't superlative. Instead, it's useful to talk with your partner to be sure that you both have realistic expectations about sex, rather than impossible dreams that can only lead to disappointment”.

Strategies for Dealing With Sexual Problems

Most of the sexual concerns experienced by people with MS can probably be dealt with through information about how to enhance their sexual lives, improved communication, reduction of stereotyped sexual performance expectations, occasional psychological support from peers or others, practice of pleasurable sexual behaviours and avoidance of frustrating ones. It doesn't hurt to have adequate privacy, income and social support as well, which makes the list a little more complex than I had intended. The point is that “seeing a sex therapist”

need not be the immediate response to something perceived as a sexual problem although sex counselling and therapy are one part of the spectrum of possibilities available.

Erectile Dysfunction

The penile prosthesis is probably well known to men with “organic” erectile difficulties. One common type uses flexible rods surgically inserted into the two cavernous bodies of the penis (the corpora cavernosa) that would normally engorge with blood to cause erection. The implants provide permanent rigidity sufficient for intercourse with the disadvantage that appropriate tight-fitting underwear is needed for concealment. A more recent advance uses a hinged model that makes concealment easier. Another method implants balloon-like chambers in the two cavernosa which can be filled from a fluid reservoir under the skin by squeezing valves positioned in the scrotum just above the testicles. There are a number of modifications on each of these patterns with short-term post-surgical complications varying widely (see Schover and Jensen, 1988; Pedersen et al, 1988).

Some men with MS will have opted for such surgery, but there is no detailed follow-up data specifically on the outcomes for this group. Outcome studies on the surgery (Pedersen et al, 1988) and on patient and partner satisfaction (McCarthy and McMillan, 1990) are generally positive although much of the research in this field has been criticized for being too short term and not asking sufficiently in-depth questions (Tiefer et al, 1988). Schover and Jensen (1988) point out that the surgery cannot “improve sensation on the penile skin, or



change a man's ejaculation or capacity to reach orgasm". In a recent study of 52 men (average age 60 years, approximately two years post-surgery) and the partners of some (n=22), Tiefer et al (1988) concluded: "Positive reactions focused on the psychological benefits of reduced worry and guilt, renewed masculine self-esteem, and improved primary relationships. Negative opinions emphasized the postoperative pain, concerns over prosthesis visibility, mechanical malfunctions, reduced penis size and concomitant diminution in usable intercourse positions. Overall, patients were more positive than partners, underscoring the importance of the psychological benefits to masculine self-esteem".

Another method introduced more recently uses a vacuum constriction device in which a plastic cylinder is placed over the penis tight against the pubic area and a hand-operated pump removes air from the chamber creating a partial vacuum. This draws blood into the penis and when erection is complete an elastic ring is slipped off the cylinder around the base of the penis. The cylinder is then removed and the ring retains the erection until it is released (no more than 30 minutes recommended). This method has the advantage of being non-invasive (no surgery) and less expensive. Research on user and partner satisfaction is limited (Cooper, 1986), but effective communication and proper use are important. Information on this and other methods can usually be obtained from the urology division of any major hospital or from your doctor.

Recently, the injection of papaverine and phentolamine directly into the cavernous tissues of the penis has been used as another way of treating organic erectile dysfunction (Szasz, 1986). These drugs dilate blood vessels and relax smooth muscles in the penis thus causing erection within a few minutes of injection. Men with erectile problems are taught to inject themselves (for review of research on self-injection see Althof et al, 1989) and the results with those who remain with the procedure appear to have a positive impact for patient and partner. However, dropout rates from programs using this method are quite high (approximately 50 percent) either because of unwillingness to self-inject or potential side effects (Althof et al, 1989).

Prescription Medication

A new oral prescription medication for the treatment of erectile dysfunction became available in Canada in March 1999. A large clinical trial of sildenafil citrate (Viagra) with men having a wide variety of medical conditions found the drug was effective in improving erectile function in a significant number of the group compared to placebo. The drug may be useful for men who have MS based on positive results with men who have spinal cord injury. Results of a study specifically involving men with MS should be available in the near future. Whether Viagra has a similar effect on sexual arousal in women is currently under investigation in Canada and internationally. Viagra is available by prescription only.

One cautionary note about Viagra. It should not be taken by people who are using any form of nitrates, including the heart medication nitroglycerine. The

combination of Viagra and nirates may lead to a potentially dangerous drop in blood pressure.

With all of the above methods several issues deserve attention.

1. Do you expect it to solve relationship problems? Not likely although it may be an enhancement to an already satisfying relationship.
2. Are you likely to use it as a way of maintaining an intercourse focus to the detriment of exploring other avenues for sexual expression, some of which may be more satisfying for your partner?
3. Have you discussed it fully with your partner? Do you anticipate that it will improve your chances of finding a partner?
4. Have you had adequate testing of the neurological basis for the erectile dysfunction that led you to consider one of these methods, for example, nocturnal penile tumescence testing, pelvic reflexes, Doppler test, etc. (Goldstein, 1983). Some men may prefer these “technical” approaches in lieu of sex counselling or therapy which could do more to deal with other personal and relationship issues that may get bypassed by defining organic erectile dysfunction as the problem.

Bowel and Bladder Control and Other Issues of Hygiene

“My fear was losing control of my bladder or bowels during lovemaking and I’m sure this contributed to my (lack of) enjoyment. I say most of this in the past tense, not because the symptoms have

changed but mainly because I think we are working things through. For example, I always go to the bathroom before lovemaking and empty my bladder as much as possible”

This woman’s experience will be familiar to many people with MS. Her response was to talk with her partner and to do some advanced planning. Others might reduce fluid intake several hours before sexual activity, try sex as an hors d’oeuvre preceding rather than following the candlelight dinner, adopt positions that minimize the chance of reflex bladder activity, time antispasmodic medication for the same purpose, and have towels and a sense of humour on hand just in case.

People who communicate effectively with their partners about this issue will defuse a potential source of apprehension and uncertainty in their sexual interactions. If you are just beginning a new relationship, you may wonder if, how and when to introduce the subject. “Will I put her off and make her lose interest before we get started?”. “How do I bring it up without sounding clinical or breaking the mood?”. There are no universal answers on this one. Some people can carry off a comment such as “If I happen to wet the bed it means I’m **really** enjoying myself”. Others will prefer a more subtle approach.

Thoughtful attention to hygiene can be particularly reassuring for partners apprehensive about odours or tastes that might detract from their pleasure. Some couples bathe or shower together prior to sexual activity, or they may use pleasant scents and lubricants, all of which have the added bonus that can be arousing at





the same time. Since many of us learned negative associations about urinary and bowel functions in childhood, this area is one that deserves special understanding and communication.

Knowing how MS affects these natural functions can also help to defuse the mystery, and stigma, some people have about incontinence. The reflexes that control bowel and bladder emptying are controlled by nerves that enter and exit the spinal cord in the sacral region, the area that also mediates sexual arousal (Figure 1). Impulses travelling down the cord from the brain stimulate reflex emptying which is usually under voluntary control. MS-induced damage to nerves in the upper region of the cord can block this control while leaving the reflexes intact. The resulting condition, called “upper motor neuron bladder”, can cause the bladder or bowel reflex to be more easily triggered by quick pressure, hard laughter, genital or anal stimulation, or other such cues.

If you use a catheter, you may be able to take it out prior to sexual activity, or tape it to one side. Some men fold the tube back over the penis and put on a well-lubricated condom before intercourse.

Enhancing Sexual Relationships

Whether you have encountered any of the physical problems already discussed, you may want to find ways of altering the pattern of your sexual relationship to make it more enriching, varied, or emotionally satisfying.

For some people, improvement may simply mean a sensible adaptation to a functional problem caused by MS. Literature on these kinds of adaptations is often written for professionals who are expected to communicate it to their clients or patients (see Neistadt and Freda, 1987). For example:

1. **Mobility problems** may require that you adjust your positioning, type of caressing, or type of sexual activity when spasticity, balance or fatigue interfere. It is tempting to keep on repeating old patterns trying to make them work when some common sense adjustments may be all that is needed.

“Jill’s muscle spasms were making intercourse painful and sometimes impossible and her coordination and balance problems were making her feel less active in her love-making with John. She began planning the timing of her antispasmodic medication to coincide with their sexual activity, to lie on her side rather than her back, to position pillows to support her and help with balance, to rely on more manual caressing or oral stimulation to get her aroused, and to use a water-soluble sexual lubricant since it seemed to make intercourse more comfortable. She asked John to slow down a bit, and together they found positions that allowed her to do more touching and stroking with much less exertion.”

2. **Reduced sensation and changes in manual dexterity** sometimes affect people with MS. At sexuality workshops that I present, it is common for men and women to identify (usually privately) that



difficulty with self-stimulation is a physical problem. For many people, including those in relationships, masturbation is a relaxing means of self-discovery and tension release. For people with MS who have altered genital sensation it is also an important form of experimentation. Vibrator stimulation is a way of intensifying sensation for all women and for learning to experience orgasm for those who have yet to do so (Barbach, 1975; Heiman et al, 1976). Incorporating use of vibrators or masturbation into your sexual repertoire with a partner may require sensitive discussion. One woman who was concerned that her partner might feel inadequate, rejected, or in competition with a vibrator introduced it into their love-making together after discussing it with him and finding out that he liked the idea and thought it would be exciting for both of them.

Tom's reduced genital sensation and inability to stimulate himself with his hands meant that his partner was spending a great deal of time to bring him to orgasm through manual and oral stimulation. This was a source of frustration for both of them so they began exploring areas where he felt erotic sensation around his nipples, neck, buttocks, and thighs. They took the pressure off having orgasms and focused on sensual enjoyment and increased use of fantasy and mental stimulation. As Tom said, "I have most of my stimulation in my mind, not my penis, so it is good to be able to have that kind of enjoyment. Of course, it wasn't easy to reveal my fantasies because I thought my partner

might take it as a sign of dissatisfaction with our relationship. Luckily we have been able to sort that out by talking about it."

An important component in adapting your sexual relationship to the functional limitations of your condition is giving and getting feedback. Here's what a woman recently diagnosed with MS had to say:

"We engage in more foreplay than we used to and have found other ways of getting me "turned on", so to speak (nipple manipulation is a good one). Sometimes one side of my vagina or one area will be more sensitive than others so we kind of play around until it feels good. I think our rule in this is he doesn't constantly ask me if it feels good. I find that more inhibiting than anything else so I just tell him what doesn't feel good for me and if I don't say anything, he assumes that it's okay. I guess this is where communication comes in and each couple has to work out there own system. But there does have to be communication!"

Some people view the range of possible sexual activities not simply as "foreplay" or as "alternatives" to intercourse, but as completely worthy and acceptable sources of sexual pleasure and sharing in and of themselves. Finding the ability to be open and to communicate about exploring different ways of relating sexually is another aspect of sexual enhancement. The last 10 years have seen a growth of literature that ventures beyond the "how to" approach to sex into suggestions for maintaining or rekindling desire, variety and love (Nowinski, 1988;



McCarthy and McCarthy, 1989; 1988; Barbach, 1982; Stubbs, 1988) or for adapting to sexual dysfunctions (Kaplan, 1989; Mason and Norman, 1988). Other books emphasize sensuality, non-intercourse sexual pleasuring or other safer sex practices (Stanway, 1989; Peters, 1988).

Massage and the power of touch are also highlighted as important forms of physical communication (Stubbs, 1989; Hooper, 1988). I want to emphasize this for people with MS, particularly for those living in institutional settings, and for their partners. Touch is therapeutic and too often lacking in all of our lives. Disability can expose you to more touching of the kind that meets physical needs but less of the kind that expresses intimacy, acceptance and reassurance. Some of us get used to giving and getting touch only in a sexual context, and when sex is interrupted so is our chance to be touched. But touch that makes no sexual demands or expectations can be an important source of affirmation and tension release. Practice at giving and receiving that kind of touch requires patience. Asking for it may be difficult, although staff in hospitals or chronic care facilities are becoming more sensitive to the need for touch and to the feelings of isolation and loneliness that it can ease.

Fertility and Contraception

Women with MS ovulate and menstruate. Their biological fertility is unaltered, and they must therefore consider some method of contraception or fertility regulation if they do not wish to become pregnant. MS per se should not preclude your using any particular method of birth

control, but there are a few considerations that might apply to your unique situation. Contraceptive pills may pose a problem for women taking antibiotics, such as tetracycline, because they decrease the pill's effectiveness as do some barbiturates, hypnotics and other medications that increase liver enzymes involved in hormone breakdown (Birk and Rudick, 1986). Women requiring antibiotics infrequently might use oral contraceptives with higher doses of estrogen and shift to some other method when on medication. Immunosuppressive medications used to control the symptoms of MS may increase the risk of pelvic infection associated with the intrauterine device (IUD). The IUD may also be inadvisable for women who have strong leg spasms or reduced pelvic sensation, the latter because they might not detect signs of discomfort that signalled problems with the device. Books such as *The New Our Bodies Ourselves* (1984) and booklets like *Toward Intimacy* (Shaul et al, 1978) contain useful insights on contraception and sexuality for women with disabilities.

Birk and Rudick (1986) also advise regular (every 6 months) gynecological examinations, including breast examination and Pap smear, for women being treated with prednisone, azathioprine, or other immunosuppressive medication. If you want to feel a little more "in charge" of gynecological examinations, a booklet called *Table Manners* (Ferreyra and Hughes, 1982) is a helpful guide for women with disabilities. It would also make a good gift for your doctor. Women with reduced manual dexterity or loss of sensation in their hands may have difficulty with barrier



methods such as foam, diaphragm or condom. In such circumstances, condom use may also present difficulties for men with MS. However, concern about sexually transmitted diseases including HIV infection makes it imperative that partners communicate clearly on this issue and that they consider not just contraception but also STD prevention. Condoms are most effective as contraceptives when used with spermicidal foam and those with nonoxynol 9 give added protection against HIV infection.

Men with MS are also likely to be fertile but interference with erection, ejaculation or capacity for intravaginal intercourse may prevent otherwise viable and healthy sperm from reaching their destination. Several options have been tested for collecting sperm that could then be used in artificial insemination. These include an electrical stimulation method that causes reflex ejaculation in men whose neurological impairment otherwise blocked the process (Brindley, 1980) or vibratory stimulation of the glans of the penis to initiate a similar reflex (Szasz et al, 1986). In some men with sympathetic nervous system damage, seminal fluid flows into the bladder rather than externally. If suitably treated, sperm in this fluid (retrieved by catheterization) can also be used for artificial insemination. Couples unable to conceive may also seek adoption or donor insemination.

Those considering adoption may enjoy reading the experiences of Dr. Alexander Burnfield, an English physician who has MS and his wife Penny, also a doctor. Both have published on sexuality and MS (Burnfield, 1978; Burnfield and

Burnfield, 1978), but his recent book (Burnfield, 1985) is a more personal account of living with MS including the adoption of two daughters. In their case, adoption followed infertility for reasons unrelated to MS. His account of parenting and of his children's reaction to his MS, including their own concern that they might get it, form one part of a useful book.

Pregnancy and MS

Many women are diagnosed with MS at a time in their lives when they are contemplating either starting a family or having another child. Such decisions are complex enough at the best of times, but having MS adds some specific questions for you to consider in the decision making process. The ultimate decision about whether or not to have a child is your own, but it is only when you are aware of the various factors involved that you can make informed choices for yourself and your family. Here is a summary of some common concerns gleaned primarily from a recent study at the MS Clinic in Vancouver, B.C. (Sadovnick et al, 1990).



Pregnancy is unlikely to be a contributing factor in the onset of MS, and exacerbation of symptoms is not more likely to occur either during the course of pregnancy or up to six months following delivery. A study at the Vancouver MS Clinic compared the rate of flare-ups



during pregnancy with the rate for the women themselves prior to becoming pregnant and the rate for non-pregnant women with MS following very similar disease courses. MS flare-ups did not occur more often than expected.

Relapses of MS during pregnancy and following delivery tend to be very similar to a woman's previous MS relapse(s). Knowledge of your own personal history may therefore be your best guide for your possible disease course during pregnancy. You are in the best position to assess whether you would be able to cope with pregnancy and caring for a child if you have a relapse either while pregnant or after delivery. Another factor to consider is whether or not medical intervention such as steroid treatment is usually required when you have a relapse. Women whose relapses repeatedly require such intervention may be in a difficult situation if they have a relapse during pregnancy since the possible effect of such treatment(s) on the developing fetus would have to be weighed against the possible effect on the mother of withholding treatment.

The Vancouver data found that during the **last** trimester of pregnancy, fewer relapses occurred than expected. It has been suggested that normal suppression of the immune system which occurs during pregnancy may "calm" the highly activated immune system thought to contribute to nerve demyelination in MS.

Generally, MS does not appear to affect the overall pregnancy outcome. Women with MS do not have an increased risk of stillbirths, spontaneous abortions (miscarriages) or birth defects compared with the general population. However, as

previously mentioned, various medications used to treat MS (e.g., prednisone, diazepam, tegretol, corticotrophin, azathioprine, cyclophosphamide) must be assessed on an individual basis as some of these (or combinations thereof) may be harmful to a developing fetus. In addition, women participating in MS treatment trials should be counselled about any possible risks to a developing fetus before deciding about whether or not to enter the trial. Consultation with a doctor is important throughout the pregnancy.

Breast-feeding is not recommended in the presence of some medications although it is otherwise encouraged if **energy level** and nutritional status permit. Close attention to urinary tract infections is important since multiple sclerosis and pregnancy are both associated with an increase in such infections" (Birk and Rudick, 1986). MS may preclude some anaesthetics during delivery, but overall management of pregnancy and delivery should not be out of the ordinary for women with MS. If you experience fatigue due to MS, you may wish to discuss with your doctor the possibility of a few extra days in the hospital after the birth. This may help you be more rested and ready to cope with a newborn.

An important reminder to those contemplating pregnancy is that you have to look beyond the actual pregnancy and newborn period in making the final decision. Pregnancy and the newborn period actually comprise a very small portion of the approximately 18 years of active child-rearing. The long-term course of MS cannot be predicted, and there are thus many issues which potential parents must consider in view of the very real



possibility that the MS parent may develop significant disability or ongoing problems with fatigue during the years of raising a family.

Chance that children will develop MS

In addition to concerns about relapse rates while contemplating a pregnancy, you may also worry about whether MS can be passed to your child.

Although MS is not inherited in a straightforward genetic fashion, certain genes appear to be more commonly found in the MS population compared with controls. The specific role(s) of these genes in MS susceptibility must still be clearly defined and may eventually provide a basis for better predicting who is “at risk” to develop MS within families.

At present, such estimates must rely on results from observed data on risks to relatives of people who have MS. For example, using data from the Vancouver MS Clinic, it is known that 5% of daughters of mothers with MS will develop MS during their lifetime. (Sadovnick et al, 1988) This is still a **very** low risk, although higher than the risk for the general population (0.1%). In addition, the risk changes with age. For example, if you are presently 28, symptom-free and the daughter of a mother with MS, your remaining risk to develop MS is 2.5 %. If you are symptom-free by age 40, your remaining risk will have decreased to 1%. This change with age reflects the fact that the majority of persons develop MS between the ages of 20 and 40, although the overall age of onset is 10-59 years (Poser

et al, 1984). As one ages, the remaining risk for MS decreases as the individual has passed through a portion of the “at risk” period. Thus, if you don’t have MS by age 40, you are much less likely to than if you have not developed MS by age 20 since, at age 40, you have already passed through more of the “at risk” period.

Sons of persons with MS have different risks of developing the disease depending upon the sex of the parent with MS. If a mother has MS, her son has a lifetime risk for MS of about 3%, slightly less than the 5% risk for a daughter, but still elevated over the 0.1% risk for the general population (Sadovnick et al, 1988; Sadovnick et al, 1991). If a father has MS, the risk for his son to also develop MS is virtually the same as the background rate for the general population **unless** there is a strong family history of MS (two or more family members with MS). The explanation for this apparent lack of father-son pairs with MS is unclear, but this has been a consistent finding of family studies in Canada. (Sadovnick et al, 1991)

Medications

Among the medications sometimes prescribed for people with MS, antispasmodic drugs may reduce sex drive, tranquillizing drugs may interfere with emission and ejaculation in men, and some antidepressant drugs may inhibit erection in men and vaginal lubrication and engorgement in women. Inhibited orgasm is also reported in women taking antidepressant medication (Segraves, 1988). Some muscle relaxants and pain medications may also have these effects. People unaware of these



occasional unwanted side-effects may unwisely discontinue necessary medication when alterations in type or dosage may eliminate them.

Depression and Other Psychological Factors Affecting Sexuality

Depression and/or grief appear to be present at some time in many people with MS, particularly when the course of the disease is unfavourable (Bezkor and Canedo, 1987; LaRocca, 1984; Kelly, 1985). This kind of depression is not just the occasional “down” feeling that all of us get, but a more prolonged period of sadness linked with other changes (sleep disturbances, loss of appetite, etc.). Depression involves a reduction in drive-motivated behaviours including reduced sex drive, one of a constellation of symptoms that can reinforce feelings of personal and social isolation. Focusing on sex drive issues in such cases is treating the symptom rather than the cause. Psychotherapy, sometimes in conjunction with anti-depressant medication, offers effective treatment for this common but under-recognized experience of people with MS. Indeed, psychological stress that requires counselling is an indication of the demands MS can place on coping mechanisms (Stenager and Jensen, 1988).

In a review of the literature on psychosocial factors, stress and MS, LaRocca (1984) concluded that there is no such thing as an “MS personality”. “Self-esteem may be seriously challenged by the illness”, he noted, but not to the extent that people with MS have lower self-esteem than the population in general. Furthermore, “knowledge about the illness seems to assist in the

adjustment process”. Nevertheless, stress is the enemy of satisfying sexual experience and strategies for stress-reduction may well have aphrodisiac effects.

Fatigue can have a major impact on sexual desire and activity. Fatigue is a common problem in MS. It is neither a function of muscle pathology nor a psychosomatic disturbance (Freal et al, 1984), and ways of minimizing it, as with stress, are an important aspect of maintaining a satisfying sexual relationship. Since fatigue is most likely to occur in the late afternoon and evening and to be exacerbated by heat, the timing of sexual interactions to meet your body’s schedule rather than always after the 11 o’clock news may be a good idea.

In some people, MS can affect aspects of cognitive function (Rao, 1986; Sullivan et al, 1989), particularly the thought functions that involve sustained attention, concentration, retrieval of memory, and some areas of abstract reasoning (Stenager et al, 1989a, b). Conflict over misunderstandings or poor communication in a relationship are more difficult to resolve in the face of these MS-related changes in brain function. This is an extremely sensitive area because it is not easy to acknowledge difficulty with planning, organization, and other specific tasks and even harder to have someone else point out the problem. Intelligence and ability to use language do not appear to be greatly affected, but if you have difficulty finding the right word in conversation – something that happens to most of us with age anyway – MS may well get the blame whether it is warranted or not. This



is an important issue in developing or sustaining sexually satisfying relationships. The cognitive function issue warrants more attention than it has received in the sexuality literature. Fortunately, there are helpful approaches to dealing with changed cognitive function (Sullivan et al, 1989). These can enhance daily living, reduce stress and perhaps indirectly improve sexual relationships challenged by communication difficulties arising from this problem.

Sex Counselling and Therapy

Sexual problems are an important contributor to personal and relationship stress. Many people are tempted to “let it go” when a few sessions with a capable therapist might help them to resolve their



individual concerns or to clarify relationship problems that don't simply “go away on their own”. Some of the specific sexual dysfunctions described earlier might fall into that category, particularly if they are causing conflict, or if you are having trouble communicating about them with a partner.

Seeking the advice of a counsellor or therapist does not mean you are “sick”, and it need not involve prolonged treatment or intense psychotherapy. You will not be asked to demonstrate your sexual “technique”. Sex therapists should also be experienced in individual and relationship counselling, both important aspects in dealing with sexual concerns. The therapist will probably begin by giving you **permission** to discuss sexual topics and to explore sexual feelings without the demand for performance. She or he will also give you **limited information** about your situation and offer **specific suggestions** about how to adapt to it. Professionals other than therapists may also use this method, but **intensive therapy** implies more formal treatment using a variety of procedures employed by sex therapists. You can contract with him or her (or both if you see a co-therapy team) about what you want to deal with, what it will cost, and how long it may take. Although you may feel somewhat insecure about going for this kind of professional help, **remember** that you are doing the hiring and have the right to stop the therapy any time you wish.

As people become more open about acknowledging the importance of sexuality in their lives, they also seem more willing to seek help when things are not working out. Please don't let embarrassment stop you. If you are persuaded that this is the right course of action, I must now admit that it is not always easy to find a counsellor or therapist with experience in both sexuality **and** MS. You may find that you are teaching them about multiple sclerosis, at least as it applies to you,



while they are helping you sort out your particular concern. Possible sources of advice and referral include:

1. Your own doctor. Plan your questions in advance and bring them up early in the visit so you don't feel rushed;
2. Your local MS Society chapter or MS clinic;
3. Your local medical association;
4. The Sex Information and Education Council of Canada. SIECCAN (416-466-5304) does not do therapy but can put you in touch with professionals in different parts of Canada;
5. The American Association of Sex Educators, Counselors and Therapists. AASECT (P.O. Box 5488, Richmond, VA 23220-0488; www.aasect.org) has a national listing of certified sex therapists although it is wise to check for experience in dealing with disability because some specialize in specific areas.

Most of you will neither need nor want therapy. But most of you will have encountered some of the issues and concerns raised in this booklet. I hope some of the content will help to sustain and nourish the positive integration of sexuality into your life and relationships.



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