

# MS *in focus*

Issue 6 • 2005

## ● Intimacy and Sexuality



multiple sclerosis  
international federation

## Multiple Sclerosis International Federation

MSIF is a unique collaboration of national MS societies and the international scientific community.

It leads the global MS movement in sharing best practice to significantly improve the quality of life of people affected by MS and in stimulating research into the understanding and treatment of the condition.

Our priorities are:

- Stimulating global research
- Stimulating the active exchange of information
- Providing support for the development of new and existing MS societies
- Advocacy

All of our work is carried out with the complete involvement of people living with MS.

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## Letter from the Editor



Sexuality and intimate relationships are a significant part of life and well-being. For most people, sexuality and its expression are a natural and important component of self-concept, emotional well-being, and overall quality of life. Factors such as culture, religion and self-esteem

contribute to how a person experiences sexuality. While MS may alter functioning, the desire for a sexual identity, love, affection and intimacy remains. Given this, sexuality may be a source of significant frustration for many people with MS.

This issue of *MS in focus* presents a discussion of intimacy and sexuality. Often these topics are not easy to discuss. This is true for people with MS as well as for many healthcare professionals. For some individuals and couples living with MS, intimacy and sexuality receive little or no priority, and instead their focus and emotional resources are concentrated on dealing with other problems related to the disease.

Whether a person is in an intimate relationship or not, it is a challenge to maintain a sexual identity and take care of one's sexual self-esteem (how one feels about oneself as a sexual being) while dealing with a chronic illness such as MS. It is particularly challenging in cultures where society places importance on qualities that are not always consistent with chronic illness, such as beauty, health and independence.

With this issue of *MS in focus* we hope to increase awareness of the fact that sexual problems are a direct result of demyelination, can be a result of other MS symptoms and that psychological, social and cultural aspects influence an individual's sexuality.

We also hope that this issue will serve as a resource for professionals who encounter difficulties in discussing intimacy and sexuality issues with people with MS.

**Michele Messmer Uccelli**, Editor

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The next issue of *MS in focus* will be on Rehabilitation. Send questions and letters to [michele@aism.it](mailto:michele@aism.it) or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

## Editorial Statement

The content of *MS in focus* is based on professional knowledge and experience. The editor and authors endeavour to provide relevant and up-to-date information. Information provided through *MS in focus* is not intended to substitute for advice, prescription or recommendation from a physician or other healthcare professional. For specific, personalised information, consult your healthcare provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# Introduction to intimacy and sexuality in MS

By Fred Foley, PhD, Bernard Gimbel MS Center, New Jersey and Albert Einstein College of Medicine, New York, USA

Multiple sclerosis can cause changes that affect one's usual ways of expressing sexuality. Everyone with MS retains the capacity to give and receive love and pleasure, although creative problem-solving is sometimes necessary to find avenues for intimate expression. Understanding how MS symptoms might affect intimacy and sexuality represents a crucial step towards overcoming obstacles effectively. Whether one is newly diagnosed, physically disabled, young, mature, single or in a committed relationship, MS does not diminish the universal human need to give and receive love and intimate pleasure.

## Sexual changes in MS: frequency and characteristics

Studies have been completed on the prevalence of sexual and relationship problems in MS in a number of countries. Although normal sexual function changes throughout the lifespan, MS can affect an individual's sexual experience in a variety of ways. Studies on the prevalence of sexual problems in MS indicate that 40-80 per cent of women and 50-90 per cent of men have sexual complaints or concerns. The most frequently reported changes in men are a diminished capacity to attain or maintain an erection, and difficulty having an orgasm. The most frequent changes that women report are a partial or total loss of libido (sexual desire), vaginal dryness/irritation, diminished orgasm, and uncomfortable sensory changes in the genitals.

Sexual changes in MS can best be characterised as primary, secondary, or tertiary in nature. **Primary sexual dysfunction** stems from changes to the nervous system that directly impair the sexual response and/or sexual feelings. Primary disturbances can include partial or total loss of libido (sexual desire), unpleasant or decreased sensations in the genitals, decreased vaginal lubrication or erectile capacity, and decreased frequency and/or intensity of orgasm. **Secondary sexual dysfunction** refers to MS-related physical changes that indirectly affect the sexual response. Bladder and/or bowel dysfunction, fatigue, spasticity, muscle weakness,



problems with attention and concentration, hand tremors, and non-genital changes in sensation are amongst the most common MS symptoms that can cause secondary sexual dysfunction. *Tertiary sexual dysfunction* results from psychosocial and cultural issues that can interfere with sexual feelings and sexual response. Depression, performance anxiety, changes in family roles, lowered self-esteem, body-image concerns, loss of confidence, and internalised beliefs and expectations about what defines a “sexual man” or a “sexual woman” in the context of having a disability, can all be expressions of, or contribute to, tertiary sexual dysfunction.

### **The central nervous system and sexual response**

Sexual response is mediated by the central nervous system – the brain and spinal cord. There is no single sexual centre in the central nervous system. Many different areas of the brain are involved in various aspects of sexual functioning, including sex drive, perception of sexual stimuli and pleasure, movement, sensation, cognition, and attention. Sexual messages are communicated between various sections of the brain, thoracic (upper), lumbar

(middle) and sacral (lower) spinal cord and genitals throughout the sexual response cycle. Since MS can result in randomly distributed lesions along many of these myelinated pathways, it is not surprising that changes in sexual function are reported so frequently. The good news is that there are likely to be neurologic pathways that mediate aspects of sexual feelings and response that are widely distributed and therefore unaffected by MS lesions.

The subsequent articles in this issue of *MS in focus* will discuss in greater detail the important aspects of sexual functioning as related to MS, including strategies for enhancing sexual desire, communicating with a sexual partner and managing other symptoms of the disease that can inhibit sexual expression.

Unfortunately, healthcare providers rarely bring up the subject of sexuality, because of personal discomfort, lack of professional training in this area, or fears of being overly intrusive. It is critical to discuss changes in sexual feelings and strategies and treatments that are available to enhance sexuality.

### **Body Mapping**

**Developing a “sensory body map” to explore the exact locations of pleasant, decreased, or altered sensations can improve intimate communication and set the stage for increasing pleasure.**

Conduct a “sensory body mapping” exercise (15 – 20 minutes):

Begin by systematically touching the body from head to toe (or all those places you can comfortably reach).

Conduct this exercise without your clothes on, in a place that is private, relaxing, and a comfortable temperature.

Vary the rate, rhythm, and pressure of your touch. Note areas of sensual pleasure, discomfort, or sensory change. Alter your pattern of touch to maximise the pleasure you feel (without trying to obtain sexual satisfaction or orgasm).

Next, inform your partner of your “body map” information and instruct him/her in touching you in a similar fashion.

Have your partner provide the same information for you (about his or her “body map”). Take turns providing pleasure to each other, without engaging in sex or trying to orgasm.

Remember, the emphasis is on communication and pleasure, not sex or orgasm. This exercise sets the stage to rediscover pleasure in the face of reduced desire.

# Sexual dysfunction in women with MS

By Farida Sharon van Rey, MD,  
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Radboud, Nijmegen, The Netherlands

Female sexual dysfunction is very common in women with neurological conditions, including MS. The majority of women with MS suffer from sexual dysfunction at some stage of the disease. Compared to a general female population, in which 20-50 per cent of women are affected, the prevalence of sexual dysfunction is estimated to be as high as 80 per cent in women with MS. Sexual dysfunction has a major impact on quality of life and interpersonal relationships. For many women it is a physically disquieting, emotionally disturbing and socially disruptive disorder. In spite of its high prevalence, these aspects of an individual's well-being have been considerably neglected until recently, making female sexual dysfunction a very important but often overlooked symptom of MS.

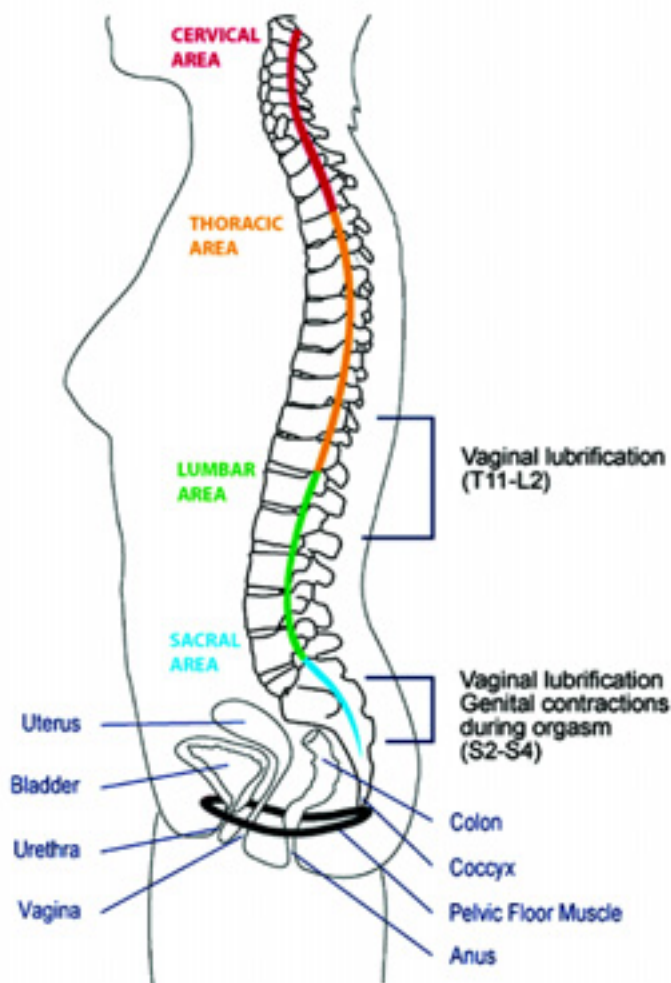
## How the body behaves during the sexual response

Two basic physical processes that occur during the sexual response: vasocongestion and myotonia.

Vasocongestion refers to the concentration of blood in the blood vessels and the tissues of the genitals and breasts. In women, this inflow of blood causes the clitoris to enlarge, the labia to swell, and the vagina to lubricate.

Myotonia, or neuromuscular tension, refers to the increase of energy in the nerves and muscles. During sexual activity, myotonia takes place throughout the body, not only in the genital region, but throughout the trunk, particularly in the breast and chest wall.

For women, vasocongestion in the vaginal walls causes vaginal secretion to seep through the vaginal



*The sexual response centres in women*

lining, moistening the inner surface of the vagina. The amount of lubrication or “wetness” present in the vagina does not necessarily coincide with a woman's degree of arousal or desire for intercourse. Swelling of the clitoris and of the labia also occurs in response to vasocongestion during the excitement phase. In addition, the inner two-thirds of the vagina lengthens and expands, the cervix and uterus elevate, and the outer lips of the vagina flatten and separate. Nipples may become erect, breasts slightly enlarged, and the veins in the breasts may appear more visible.

### **How and why MS can affect sexual functioning**

Sexual dysfunction in women has many causes and effects. Abnormalities in blood circulation, hormonal state, nerve functioning and mental well-being may influence sexual functioning. Therefore, one or more of these factors can result in sexual dysfunction. Lesions in the brain can interfere with the interpretation of sexual stimuli as arousing, while lesions of the spinal cord can interfere in the transmission of arousing nerve signals to the genitals. Lesions in the sacral (lower) spinal cord can also cause primary sexual dysfunction, by inhibiting or preventing vasocongestion, resulting in diminished or absent clitoral swelling and/or vaginal lubrication.

In primary sexual dysfunction, MS lesions in the spinal cord may make it difficult to sustain clitoral/vaginal engorgement during the plateau phase (between arousal and orgasm). In addition, sensory changes in the genitals can interrupt or diminish nerve signals that initiate and/or maintain vasocongestion at both the spinal cord and cerebral cortex (brain) levels.

### **Types and frequencies**

Approximately 80 per cent of women with MS experience sexual dysfunction at some time during the course of the disease. Some women stop engaging in sexual relations while others (approximately 40 per cent) have reported that participating in sexual relations is significantly unsatisfactory. Symptoms most commonly reported include reduced genital sensation (48 per cent),

reduced vaginal lubrication and difficulty with arousal (35 per cent), and difficulty or inability reaching orgasm (72 per cent). Pain during intercourse is also a frequently reported symptom in women with MS, which may be due to vaginal dryness, spasticity or hypersensitivity.

### **Assessment**

Since the sexual response in women with MS is related to many different factors, a comprehensive assessment of all these aspects must be taken into account. An evaluation should consist of a full medical history, physical examination and pelvic examination. Although sexual dysfunction in women with MS often has a neurological cause, its evaluation is not always included in routine clinical practice. Often it is possible for a clinician to become aware of a problem and begin to evaluate it based on information provided by the individual during the visit, in response to a few relevant questions. Initiating these questions is not always part of the healthcare professionals' routine, with the result that important information is missed by the professional and problems experienced by the person with MS are left unaddressed.

### **Possible treatments**

Oestrogen creams may be useful for women experiencing vaginal dryness, pain or burning. Another treatment for these symptoms is a vaginal suppository, although this form may not be available in all countries. Unfortunately, many of the medications that appear to be effective for the treatment of male sexual dysfunction related to MS have proved either to be ineffective for other symptoms of female sexual dysfunction or have not been studied fully at this time.

### **Conclusions**

Sexual dysfunction is highly prevalent among women with MS. Assessment and treatment of these problems is complicated. Addressing sexual problems during routine visits is important in identifying and managing symptoms that can have a negative impact on an individual's personal life as well as on the life of the couple.

# Sexual dysfunction in men with MS

By Douglas W. Lording, Medical Director, Melbourne Andrology Centre, Victoria, Australia

Sexual activity for men usually requires the co-ordination of arousal, penile erection and orgasm including ejaculation, along with the many other emotional and relationship components that are integral for satisfaction. Direct disruption of nerve pathways controlling erection and ejaculation are common.

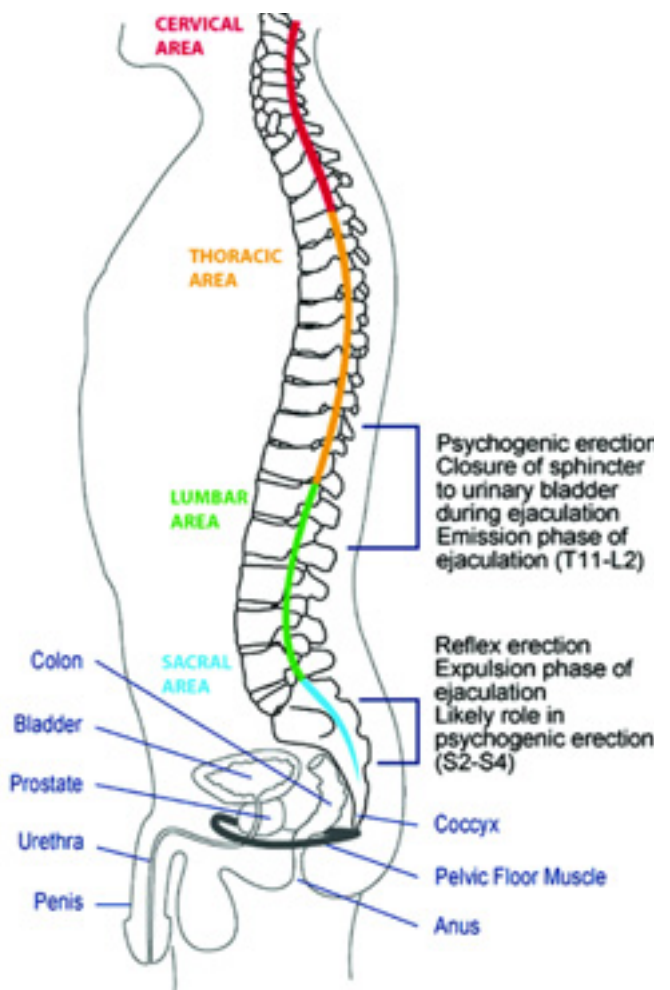
## Erectile dysfunction

An erection occurs when there is relaxation of the muscle cells in the wall of the penile blood vessels and the erectile tissue, leading to the penis filling with blood. Relaxation of these muscle cells is initiated by nitric oxide (NO) release from nerves coming from the lower spinal cord. The messages transmitted by these nerves usually arise in the brain and pass down to the lower spinal cord. Erectile dysfunction (ED) is the commonest sexual dysfunction in men and usually is due to disease of the vascular or neurological systems, but psychosexual influences are also important. ED can have a major impact on self-esteem, relationships and general well-being.

In men with MS, lesions in the spinal cord that interfere with the passage of nerve impulses from the brain may cause ED. The limited studies of men with MS indicate that ED is a frequent symptom, often affecting younger men and sometimes affecting fertility.

## Ejaculatory dysfunction

At ejaculation there is widespread muscle contraction in the pelvic area that leads to expulsion of the semen and much of the sensation associated with the broader response of orgasm.



## *The sexual response centres in men*

These responses are also triggered by nerve impulses that traverse the spinal cord from important brain centres.

Often, delayed ejaculation and complete failure of ejaculation (anejaculation) are caused by disruption of the nerve pathways and may be part of a broader orgasmic failure.



Ejaculatory disturbances also occur in MS, although there is less information about the prevalence. Anti-depressant medications (see page 16) that may be used in MS often cause ejaculatory problems as a side-effect. Some men with MS may develop premature ejaculation because of anxiety about their disease.

### **Sexual desire**

Testosterone is active in several brain centres important for sexual thoughts and desire (libido) and low levels are associated with depression and obesity, both of which can relate to MS. Frequently, desire is affected by factors other than the direct physical component of the disease, and this is particularly so in MS where other physical and psychological factors, such as fatigue, may play a major role.

### **Clinical assessment**

Not all men with ED (or even health professionals) find it easy to talk about sex, and they may not raise this distressing issue. It is important to note that sexual dysfunction is diagnosed by taking a careful history; there are no diagnostic tests. Men with MS may have other causes of sexual dysfunction and the assessment should take this into account. Simple blood tests to exclude diabetes, high cholesterol and testosterone deficiency are recommended. Careful assessment of the impact of medications and substance use is important.

The importance of assessing both the man with MS and his partner cannot be over-emphasised, particularly if initial treatment is not successful. This will require more developed skills that not all doctors will have.

### **Treating erectile dysfunction**

The neurologist or MS nurse should ask men with MS if they are having erectile dysfunction. If they do, the impact of this important disorder needs to be assessed and, if it is considered significant, a full range of treatment options should be discussed. Treatment is usually erection-promoting medications rather than treating the

underlying disorder. However, consideration should always be given to improving potentially reversible aspects. Drugs used to modify MS progression also could help.

The most commonly used medications act to enhance the relaxation of muscle cells in the penis. Sildenafil, tadalafil and vardenafil all act in this way through a similar mechanism. They are safe, well-tolerated medications and observation of their use in MS and spinal cord injury confirm a high efficacy, with about three-quarters of men experiencing satisfactory outcomes.

Education about how to achieve the best results is the most important aspect of the use of these medications. They need to be taken at least half an hour before sex, but some couples find the idea of premeditating their sexual experience off-putting, and this often interferes with treatment. Normal sexual stimulation is required to initiate the erection, therefore the couple needs to be in the mood for sex. Apprehension about the outcome may result in less than optimal results for the first few doses. Persistence, medical review and re-instruction are important for successful results.

### **Adverse effects**

These drugs can cause mild headaches, flushing, nasal congestion, indigestion and muscle aches, but these adverse effects usually do not preclude their use. When sildenafil was launched, much was said of possible adverse cardiac effects and

### **Tips for successful treatment**

- Discuss sexual dysfunction
- Involve both partners
- Go through the history carefully
- Do not forget non-MS causes
- Use medications properly
- Consider sex in broad terms
- Be prepared to experiment

this still worries some men and their partners. There is a potentially harmful reaction with all these drugs when used with nitrates (mainly used to treat angina), and men with active heart disease, for whom the level of physical activity during sexual intercourse is potentially dangerous, should use these drugs with caution.

### **Alternative ED treatments**

If these drugs do not work or cannot be safely used, injecting drugs into the penis or the use of mechanical aides may be helpful. Prostaglandin E1 can be injected directly into the penis. This relaxes the muscle cells and usually induces a hard, lasting erection. Significant dexterity and common sense are essential for self-injection. Penile pain, nodular scarring within the erectile bodies and unduly prolonged erection may occur. The dosing regimen prescribed must be followed strictly.

Some men with partial ED can obtain a good erection using a penile ring, usually combined with a vacuum device. The latter draws more blood into the penis while the ring, applied after blood flow into the penis is sufficient, reduces blood flow out of the penis. If all else fails, a penile



prosthesis can be implanted so that cylinders implanted into the shaft of the penis can be filled from a fluid reservoir placed in the scrotum.

### **Getting the best from ED medications**

1. Ensure mechanism of action is understood, in particular:
  - a. Timing of dosing
  - b. Need for normal sexual stimulation
  - c. Effect of food and alcohol
2. Allow at least four attempts at using the medication
3. Address secondary and tertiary sexual dysfunction
4. Review outcome of treatment after first month
5. Remember support and understanding are paramount

### **Treatment of ejaculatory disorders and low desire**

Unlike ED, there is no medication that acts directly to improve ejaculatory problems or low desire. Emphasis will be on optimising physical and emotional well-being. The ED drugs are often tried where there is difficulty achieving ejaculation and orgasm, as there is often a degree of ED as well. In addition, there is usually heightened stimulation with a harder erection. Different positions help some men to be more stimulated and some benefit from mechanical assistance, for example using a vibrator.

Couples should be reassured that satisfying sex can be achieved without full erection and penetration, and that partner satisfaction can be achieved by a variety of stimulating techniques.

# Secondary causes of sexual problems

By Dorothea C. Pfohl, RN MSCN, MS Center Clinical Co-ordinator,  
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MS changes can affect sexual response by making sexual activity difficult physically and emotionally. Symptoms common to MS, such as fatigue or changes in muscle tone, lack of coordination or pain, can frustrate sexual expression and extinguish desire. Bowel and bladder dysfunction can inhibit and cause embarrassment. Cognitive changes challenge the most devoted couple, yet in the presence of any of these symptoms, it is possible to

find creative ways to keep the physical expressions of love alive.

A person who does not feel well or thinks of himself or herself as unattractive because of a less-than-perfect body may shun sex or find their love life deteriorating. People who are not in a relationship may be reluctant to date and develop new love interests. Secondary sexual dysfunction often



indirectly affects sexual response and ability to perform in both men and women with MS. Sexual complaints are common in the general population and are capable of having a profound impact on quality of life and relationships. Adding chronic illness to the picture makes problems more likely, yet such concerns and complaints are not always shared with partners or healthcare professionals. Nevertheless, strategies exist which can be employed to cope with and manage symptoms, promote intimacy, strengthen relationships and encourage sexual pleasure and expression.

### **Fatigue**

Fatigue is perhaps the most common symptom reported by people with MS, and it can be the most disabling. For a complete discussion on the different types and causes of fatigue, see Issue 1 of *MS in focus* (January 2003). Regardless of the type or cause of fatigue, it can have a negative affect on interest in sex and lead to a reluctance to initiate lovemaking, or even an avoidance of intimacy. The well partner may misunderstand this "disinterest" and loss of pleasure and resent the person with MS. This may come at a time when they are assuming additional responsibilities, coping with changing roles or it may be perceived as a personal rejection. Often, partners fear hurting the person with MS. Effective communication requires that feelings be shared and dealt with openly and honestly, thus making it possible to explore options for maintaining a satisfactory sexual relationship despite physical changes.

Energy conservation measures can be employed to manage fatigue. These techniques can be applied to sexual issues as well. Time for intimacy may need to be prioritised, perhaps for the time of day when the person with MS has the most energy. One couple set up a weekly "date" when both could take a long lunch. Planning and anticipating their time together during the day when the children were at school became a pleasure in itself. Lifestyle changes may need to be made when there are not enough hours in the day to accomplish all that needs to be done. Simplifying tasks and accepting

available help can lessen anxiety. Planning for rest time together can lessen fatigue and simultaneously meet the need for additional time together.

Medications are available which can be used to counteract fatigue, but others actually contribute to it. If medication side-effects are suspected to be worsening the fatigue, a schedule adjustment could provide respite. A dose can be timed to allow for more energy when intimacy is planned. Disease-modifying therapy schedules, like other medications, should be reviewed with a healthcare provider who can advise and educate about adjustments that minimise untoward effects. At times, a dose can be skipped or postponed to avoid the side-effect that is getting in the way of sexual performance or interest.

*Both the person with MS and the partner deserve to have their sensitivities and willingness to accept or reject various forms of sexual pleasuring respected.*



## Weakness

Muscle weakness may necessitate alterations in sexual practices. Comfort measures, such as properly placed pillows, provide additional support and can be playfully used to “set the scene” for romance. Discussing new positions and various expressions of sexuality, such as massage or oral sex, can add excitement to the relationship and boost, rather than diminish, self-image. Partners may or may not be comfortable with such variations or may be unwilling to engage in “sex play”. Both the person with MS and the partner deserve to have their sensitivities and willingness to accept or reject various forms of sexual pleasuring respected. Rejecting an alternative that compensates for limitations imposed by MS symptoms need not be a rejection of the person, and other ideas can be pursued.

De-conditioning (weakness from inactivity) can be helped by a fitness programme modified to work with the person’s physical limitations. Kegel exercises are a type of exercise that can improve decreased vaginal tone by strengthening the pelvic floor muscles. See Issue 2 of *MS in focus* (July 2003) for information on how pelvic floor exercises are performed.

## Lack of coordination and tremor

Lack of coordination may make sex and sexual expression feel clumsy, as can tremor. But besides being awkward, these symptoms may also interfere with the couple’s style of having sex. It must be remembered that persons with MS still have needs for contraception and protection from sexually transmitted disease, but previously-used methods may no longer be practical. A partner may need to help with the condom or insert the diaphragm and it may be difficult to change from being a care partner to being a lover. Again, good communication between partners and advice from professionals can minimise embarrassment and maximise closeness and pleasure.

## Bowel and bladder problems

Another source of anxiety and distress can be bowel and bladder disturbances. These problems

go hand in hand with sexual dysfunction, since nerve pathways are shared or close to each other. Incontinence, or even fear of having an accident, can cause a person to avoid sex entirely, thus depriving them of the closeness it brings.

There are many ways to deal with involuntary elimination, but discussing the possibility of losing urine or stool during sex, and having a plan should it occur defuses the situation and can allow the couple to manage their concerns without spoiling the moment. Bowel and bladder rehabilitation plans can include toileting regimens designed for the unique needs of individuals and couples. For example, steps such as limiting fluid intake for a few hours before sexual activity can be effective. For men, leakage of small amounts of urine can be managed by wearing a condom. For both sexes, simply padding the bed well can help everyone relax. Another strategy is performing intermittent self-catheterisation prior to intimacy. This technique serves to empty the bladder completely, giving the person more confidence that he or she will not be embarrassed by an accident during sexual expression.

Urinary tract infections are common in MS and are sometimes aggravated by sexual activity. Proper evaluation and treatment of bladder problems can go far to maintaining quality of life and independence. In-dwelling catheters make the logistics of intercourse difficult but not impossible. With advice from a healthcare provider, often the bag can be emptied and then clamped for a period of time. Taping a long drainage tube to a woman’s abdomen can avoid pulling and will place the catheter well out of the way. Similarly, a catheter in the penis can be folded back on itself, clamped and taped and a condom placed over it all.

## Pain

Pain can impact significantly on interest in sex as well as performance ability. Medications used to relieve pain may add to sleepiness or fatigue. Understanding the type of pain can influence the best way to manage it. Muscle tightness, intense itching and spasticity may all be called “pain”.

Medications that bring relief must be well chosen for the type of pain they treat and used in just the right dose and frequency to give relief with the least disadvantageous side-effects. An extra or well-timed dose before intimacy can often provide effective symptom management and reassure the partner that he/she is not adding to discomfort. It is also important that a symptom such as adductor spasms (which cause involuntary pulling together of the legs) is not seen as an indication of the person's interest or willingness to have sex. Again, communication is the key to avoiding misunderstanding and hurt feelings. Water soluble lubricants can make intercourse more comfortable, without predisposing to urinary tract infection.

### **Sensory issues**

Changes in sensation can also interfere with sexual pleasure (see page 5 on body mapping). Non-genital symptoms such as numbness and tingling can distract and discourage either partner. Impaired genital sensations can diminish pleasure, while heightened sensitivity may make even the lightest touch unbearable. What feels good at one time may be excruciatingly painful on another occasion. Frank discussion of needs and limitations can avoid problems, and simple solutions as well as medications can be used to enhance pleasure. Something as easy as a bag of frozen peas gently rubbed on a woman's perineum (genital area) can increase sensitivity and pleasure and can be used as foreplay. Special oils are available which encourage touch and also increase pleasure when sensation is impaired. Vibrators can be used alone or with a partner.

### **Mobility**

MS symptoms can indirectly affect the sexual response. Devices used to compensate for loss of function can also damage confidence and self-image. They may be seen as less than sexy. Canes, wheelchairs, braces and walkers are often identified with being "sick" or "old". Spontaneity can be a problem if great effort has to be made to get around. Asking for help is often difficult. It can be challenging to think of oneself as sexually desirable when confronting a body that is less than perfect, and requires extra care to maintain. Adjusting

expectations from performance-oriented sex, where intercourse is seen as the only desirable outcome, can be liberating and allows for pleasuring and sexual satisfaction despite the limitations of impaired mobility.

### **Cognition**

Cognitive changes can be amongst the most potentially damaging to the relationship, since they can undermine the person's sense of who he/she is. A partner may feel this is no longer the person they once knew. Changes in attention and concentration may be perceived as lack of interest or love, and may irreparably strain the relationship. Changes in mood, memory loss and depression can be frightening, frustrating and sometimes infuriating. All interfere with intimacy. Individual or couples counselling may be advised.

Successful management of cognitive symptoms includes creating a stimuli-saturated, minimally-distracting environment. Partners can share what will and will not be seen as exciting and what promotes passion and interest.

Many symptoms of MS are invisible while others are painfully obvious. All can impact on quality of life and sense of well-being. While life changes affect everyone, changes from MS can directly and indirectly affect sexuality. Successful management requires creativity, communication, patience and resource management so that a person is able to



# Tertiary causes of sexual problems

By Elizabeth McDonald, Medical Director, MS Society of Victoria, Australia,

Sexuality is an evolving, overall development of one's feelings of personal identity, well-being and self-esteem that involves both social and physical relationships. This is an individual lifelong process, which is influenced significantly by personal perception, social conditioning, cultural and religious factors.

## **The impact of MS on sexuality**

The onset of MS can alter a person's perception of himself or herself as an individual, altering sexual development and expressions of sexuality, and it can have a negative impact on sexual and intimate functioning. These are known as the tertiary sexual problems of MS, derived from the resultant psychological and social changes, as distinct from the direct neurological dysfunction (primary sexual problems) and the symptoms of MS (secondary sexual problems).

Whilst MS is not a disease of the whole person, it can overwhelm and challenge the perception of "self" with negative outcomes in relation to sexuality and sexual functioning. People with MS can find it difficult to see themselves as being "sexual", having sexual thoughts, desires and needs whilst at the same time identifying with the role of a person with a chronic illness.

Individuals see themselves as complete persons in terms of their roles within families, friendship circles, sporting clubs, activities and occupations. Any feelings of loss of control over events or unplanned changes because of MS can affect one's confidence and self-esteem and alter the dynamics of relationships, especially close and intimate ones.

The diagnosis of MS, combined with the unpredictable nature of relapses and the uncertainty of disease progression, often occurs at a time when dreams and plans for the future are being formulated and relationships and careers established. The diagnosis of MS may well cloud an individual's expectation of the future. This can result in reactions of grief, anxiety and depression, lowering self-esteem and reducing confidence. Such feelings may cause reduced sexual interest and withdrawal from sexual activity.

The fear of potential or actual disability can have a negative impact on the perception of body image. People with MS may feel less sexual or sexually attractive. This is particularly evident in cultures where desirability is associated with beauty, fitness and health. Sexual feelings and sexual activity are not just for those who are young and able-bodied, yet this is the message continually transmitted by the media.

Increasing disability can bring with it changes in domestic routines, reduction or cessation of employment and reduced social interaction. This can be very distressing for those who have seen their primary role as the wage earner or the homemaker, for example. Disability can also lead to dependency on others for personal care. If the partner provides this care it can be very difficult to separate the role of carer from that of intimate lover. Visiting carers, nursing and domestic services intruding into the home can leave people with MS feeling exposed in all areas of their life, with little private time.

## DRUGS COMMONLY USED IN MS THAT AFFECT SEXUAL FUNCTIONING

Although changes in sexual desire, performance and satisfaction often occur as a result of MS, they may also be a consequence of some medications. (Currently, the vast majority of the side-effects listed below are noted by manufacturers to be "infrequent" or "rare".)

Drug	Symptoms treated	Drug effect on sexual function
Fluoxetine	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Uncontrollable laughing or crying</li> <li>• Fatigue</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased libido</li> <li>• Delayed or absent ejaculation</li> <li>• Inability to achieve orgasm (known as anorgasmia)</li> <li>• Persisting, painful erection of the penis occurring without sexual stimulation (known as priapism) Anyone experiencing this should seek medical help immediately</li> <li>• Menstrual irregularities</li> <li>• Secretion of breast milk (known as hyperprolactinaemia or galactorrhoea)</li> </ul>
Fluvoxamine	<ul style="list-style-type: none"> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased libido</li> <li>• Delayed or absent ejaculation</li> </ul>
Sertraline	<ul style="list-style-type: none"> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased libido</li> <li>• Inability to achieve orgasm</li> <li>• Menstrual irregularities</li> <li>• Enlarged or painful breasts</li> <li>• Irritation of the vaginal lining (vaginitis)</li> <li>• Inflammation of the head of the penis and foreskin</li> <li>• Secretion of breast milk</li> </ul>
Paroxetine	<ul style="list-style-type: none"> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased libido</li> <li>• Delayed or absent ejaculation</li> <li>• Inability to achieve orgasm</li> <li>• Secretion of breast milk</li> </ul>
Citalopram	<ul style="list-style-type: none"> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased libido</li> <li>• Delayed or absent ejaculation</li> <li>• Inability to achieve orgasm</li> </ul>



Dealing with the impact of MS and symptoms can leave one neglecting the emotional and psychological aspects of life in general. Simply attending to the physical needs of life's daily activities can leave little time or energy for emotional contemplation and intimate relationships. This is particularly evident if fatigue is experienced as a symptom of the MS.

It is important to remember that people with MS are not isolated and living in a vacuum; their worries and concerns affect others. Conflict can become apparent in established relationships if these factors are not recognised and addressed with ongoing and honest communication. Not uncommonly, resulting misunderstanding, resentment and feelings of rejection by the partner occur as they see MS becoming the dominant focus.

### **Management of tertiary sexual problems**

People with MS who experience problems with sexuality need to allow themselves time to assess their overall situation and to feel confident about communicating their difficulties to those close to them. Whilst this is not always easy, literature on MS and sexuality can provide useful information and help transcend feelings of isolation and uniqueness. There is also information on treatments and sexual aids that are available. Such information can be useful for partners to read and discuss together. Deciding on a time and a peaceful setting to talk about problems of sexuality helps to create an atmosphere of mutual commitment. It is important to be gentle and express feelings without blame or accusation. People with MS and their partners should explore the areas of concern slowly, listen to each other carefully, as frequently misunderstandings and resentment are the result of poor or no communication, and respect each other's opinions. It is important to remember that sexuality is not just about physical intercourse. Sexual pleasure can be gained, and given, by creating special times, places and rituals. This takes time, effort and nurturing.

It may also be of benefit to seek further help

relating to problems of sexuality from health professionals. Whilst bringing up the topic can be difficult and embarrassing for people with MS, this can also be so for some doctors and health professionals. It is important to find an MS healthcare provider with whom one feels comfortable, or seek a referral to someone specialising in this area. Going together, and with pre-written questions, can be helpful and provide the focus for initial consultation.

For health professionals the key to managing tertiary sexual problems in MS is firstly to identify what issues are having a negative impact on the well-being and sexuality of the individual. This includes identification of primary and secondary sexual problems, as well as the psychosocial factors and their complex interaction. Of prime importance is to recognise the person with MS as a whole person in the context of lifestyle, values, roles, desires and relationships. Management depends on frank and open communication about sexual issues. Treatment of any underlying depression and anxiety may require medication and psychological counselling and the provision of ongoing monitoring and support.

Counselling can help individuals to explore feelings and facilitate discussion in a respectful and professional way. Negative emotions such as guilt, anger and resentment can be identified, seen in context, and worked through, in a non-judgemental environment. Topics perhaps seen as too embarrassing to discuss alone, can be discussed in an open and supportive atmosphere. Strategies for improving the situation, or adopting new ways of considering and developing sexuality, can be introduced.

Sexuality is an important aspect of human life and must not be neglected when considering the impact of MS on an individual. Increasing awareness and acknowledgement of the effects of MS on sexuality have greatly improved the management and treatment options available for people with MS experiencing difficulties in this area.

## TALKING ABOUT INTIMACY AND SEXUALITY IN THE HEALTHCARE SETTING

Sexual dysfunction often accompanies MS and may significantly affect the intimate relationships and quality of life of people with MS and their partners.

Discussion of intimacy and sexuality is very important but can be difficult for both people with MS and healthcare professionals. Often they avoid bringing up the subject of sexuality. This may be due to personal discomfort, lack of professional training in the area, or a fear of being overly intrusive. On the other hand, intimacy and sexuality are difficult subjects for the person with MS as well. This may be because one is unaware that the problem could be related to the disease, embarrassment, fear of being judged or due to cultural barriers.

Below are key issues to bear in mind, in order to discuss this important topic effectively while minimising feelings of anxiety and embarrassment as much as possible.

### FOR PEOPLE WITH MS

- An unsatisfactory intimate and sexual life does not have to be part of having MS.
- There are no rules for whose "job" it is to discuss sexual problems, so talk to the healthcare professional with whom you feel most comfortable.
- You may be experiencing a problem for which there is a solution.
- Do not wait until you reach a crisis to discuss problems.
- Open communication with your partner is vital.
- Once the discussion has been initiated, write down questions between visits so as not to forget anything.
- Keep an updated list of medications to review during each visit, since a number of medications can negatively influence sexual functioning.
- Ask your healthcare provider for written material that you can read on your own and discuss later, if desired.

### FOR HEALTHCARE PROFESSIONALS

- Silence on the subject of sexual problems does not mean that they do not exist.
- Set the example of how intimacy and sexuality should be discussed: openly and without embarrassment.
- If you are not comfortable discussing this topic, it is important to seek assistance in order to feel more prepared.
- Make questions about intimacy and sexuality part of every interview since symptoms and problems may change. The individual may become more comfortable to discuss them over time.
- Often providing basic MS information that relates to sexuality can be helpful. For example: that sexual problems are common in MS, part of the disease symptoms, can occur together with urinary problems, etc.
- Obtain written material to offer to people with MS and their partners.
- Become familiar with the referral process for people with MS needing information on sexuality, even though it may not be part of your regular responsibilities.



*"In education courses for nurses newly working with people with MS, role-playing provides the opportunity for them to develop a personal approach to discussing sexuality and intimacy and helps them to become more comfortable with the topic." Roberta Litta, Dir. Professional Education, Italian MS Society*

## WHERE TO LOOK FOR ADVICE AND REFERRALS

- **Health professionals**
- **Family planning centres**
- **Disability information advisors**
- **Community gay rights organizations**
- **Newsletters** – for example ABLED! (Active Beautiful Loving Exquisite Disabled Woman). Quarterly newsletter. Focuses on body image, sexuality, family concerns, and other issues relevant to women living with disabilities. To subscribe, send a donation (\$10.00/year suggested) to ABLED Publications, 12211 Fondren, Suite 703, Houston, TX 77035. Tel: 713-726-1132. Fax: 713-726-8006. Web site: <http://abledwomen.org>.

### • Books

*Sexuality and Multiple Sclerosis* by Michael Barrett. MS Society of Canada, 1991 (available in different languages).

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

*The Joy of Solo Sex* by Dr Harold Litten, Factor Press, Paperback, 1996.

*Sex for One: The Joy of Self Loving* by Betty Dodson, Three Rivers Press, 1996.

### • 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 for \$3.00 Write: SIECUS, 130 West 42nd Street, Suite 350, New York, NY 10036. Tel: 212-819-9770. The bibliography is also available free on the Web at [www.siecus.org](http://www.siecus.org).

### • Journals

*Sexuality and Disability* is a journal that publishes scholarly articles on rehabilitation, disability, and sexuality. It also publishes guidelines for professional clinical practice, case studies, and information for consumers. Kluwer Academic/Human Sciences Press, Inc., 233 Spring Street, New York, N.Y. 10013-1578 USA. [www.kluweronline.com](http://www.kluweronline.com)

### • Catalogues

A number of discreet catalogue services are available that sell sexually oriented materials and promise anonymity. Their products may be helpful to both disabled and non-disabled people. Some include: *Special Edition Catalog for Disabled People*. A catalogue of sexual aids, books, resources, and information. \$4.00 each. Xandria Collection, P.O. Box 31039, San Francisco, CA 94131. Tel: 800-242-2823. [www.xandria.com](http://www.xandria.com)

*Good Vibrations* provides a mail-order and Internet catalogue of sexual aids, books and videos. Good Vibrations, 938 Howard Street, Suite 101, San Francisco, CA 94103. Tel: 800-289-8423. [www.goodvibes.com](http://www.goodvibes.com)

### • Websites

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. It has an archive of mainly educational books and videos [www.sexualhealth.com](http://www.sexualhealth.com)

The Ann Summers web page has a catalogue of adult sex aids, books and videos [www.annsummers.com](http://www.annsummers.com)

The youtopia web page has a catalogue of adult sex aids, books, DVDs, clothing and accessories [www.youtopia.ltd.uk](http://www.youtopia.ltd.uk)

The Sinclair Intimacy Institute has a catalogue of adult sex education videos and DVDs [www.intimacyinstitute.com](http://www.intimacyinstitute.com)

### • Other resources

*The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19* is a 19-item self-report instrument that measures primary, secondary, and tertiary sexual dysfunction in MS. It is used to assess these aspects of sexuality, and can be utilized to educate healthcare providers about which aspects of sexuality require attention. Many MS societies have advisors, toll-free lines, publications and groups for specific sexual orientations (for example GLAMS in the UK and LeHoMS in Norway).

# Your questions answered

Readers of **MS in focus** pose questions to the Editor, Michele Messmer Uccelli.

**Q. Excessive oral secretions (saliva) make kissing unpleasant and unromantic for both. Kissing is a cornerstone to intimacy and sexual activity. I find this a real problem. While excessive saliva may not be a major issue itself, it adversely affects intimacy and sexual activity. I would love to find a solution to this problem. Regards, Warren**

**A.** Increased salivary flow, also known as sialorrhea or ptyalism, has not been reported as a symptom of MS. When excessive salivation is seen, it is usually related to swallowing difficulty, causing some pooling of saliva in the mouth. Some medications can induce sialorrhea, so you may want to discuss any medications you are taking with your physician to understand if one of them may be causing you to produce excessive saliva. It may also be a problem related to another medical condition. Having MS does not, unfortunately, protect people from other illnesses. For this reason, it is important to consult your primary care physician regarding your concern.

**Q. I have heard that Viagra can help women with sexual problems. Is it true? Thank you, A.**

**A.** Sildenafil (Viagra™) is used in the treatment of primary sexual dysfunction in men, particularly erectile dysfunction. When studied in females with MS, sildenafil was not found to be useful, and so is not indicated for treating sexual dysfunction in women.

**Q. I am tired nearly all the time, but when I'm feeling less tired, my husband usually**

**is. This means that the opportunities to spend intimate time together are very irregular and almost non-existent. I have always initiated sex and I'm sure that my husband feels that this should still be the case. I would like to share so much more, such as touching, talking and sharing. How can I let him know that I'm not just a "medical problem", and let him see me as a person who still needs a little titillation and excitement?**

**Thanks, BA, Australia**

**A.** It is important to separate the MS from the rest of the person. It sounds as if you already know this though. It is also important that the other person is aware of your feelings. This is only accomplished through honest discussion. MS may require couples to revise their usual ways of approaching sex and intimacy (in your particular case you may not always be the "initiator"). It is also important to agree, as a couple, that intimacy is not about intercourse alone, but, as you mentioned, touching, talking and sharing.

What might happen in a couple is that one member believes that, for the other person, intercourse is the ultimate goal of intimacy. But when it is discovered that this isn't the case, both people feel less under pressure and they are freer to talk about other ways of being intimate.

Finally, there are a lot of strategies on how fatigue can be managed so that it does not interfere with sexual expression. See Issue 1 of *MS in Focus* (January 2003) on Fatigue for further information.

# Interview with Rolande Cutner

Rolande Cutner is a successful, international lawyer in Paris and New York, a very active member of the board of the French MS society “Ligue Francaise Contre la Sclerose en Plaques”, and the French representative on the People with MS International Committee. Rolande also has primary progressive MS.

**When were you diagnosed with MS?**

In April 1992, with primary progressive MS, but the first symptoms around 1986.

**Were you in a relationship/married at that time with children etc?**

I did not have children. I was divorced and dating a lot.

**Do you think that MS influences your relationship with (potential) partners?**

Absolutely, yes. Who wants to be stuck with a woman who might become paralysed down the road?

**Do you feel that your self-image or self-esteem, as a woman/partner/sexual being has changed due to MS?**

Yes. During the period when I did not know what was wrong with me and after being diagnosed, I tried, unsuccessfully, to hide my condition. My self-image and my self-esteem as a woman were damaged as long as I tried to hide the diagnosis. When I accepted the fact that I had MS, and when I decided that I had to fight MS, I felt better and that fact immediately improved my relationship with men.



*Rolande Cutner*

**Do you feel that others (e.g. partner, healthcare professionals) see you differently in terms of your role as a woman, partner and sexual being, because you have MS?**

With a diagnosis of MS, people do not see you as a woman anymore, a woman who could go to bed, make love, and participate in sexual activity. It is your responsibility to show others that you are still a woman and still a human being with sexual desire, who wants to participate in sexual activity. You must take charge of your sexual life – be a fun and sexy woman – even with MS, and perhaps even more so than before.

**In your opinion/experience, do you feel that people with MS may have limited opportunities to express themselves sexually or to participate in relationships?**

People with MS do not have to have limited opportunities to participate in relationships. If you are caring, loving and giving, as well as a beautiful person, you can connect. It's important to keep in mind that MS is not an excuse to sit around in flannel pyjamas, hair rollers and no make-up. The secret is taking control. In searching out ways to attract a partner, you have to change how you thought about yourself before MS. You must reach out and try to establish relationships.

**Have you made changes to your lifestyle/way of thinking in order to maintain or enhance intimacy and sexuality since being diagnosed with MS?**

Yes, I made a lot of adjustments. I became unpretentious and generous and I am not afraid of rejection anymore. And the level of what I am willing to give up for love is much greater. Now, I would even sacrifice my fabulous job to be with the man I love if I were asked to. I think having MS encourages you to make extraordinary changes in your life.



The Norwegian MS Society has a number of members who are gay men and lesbians. Via an article in "MS matters", Issue 47, 2003, the Society learned that the MS Society of Great Britain and Northern Ireland had created a support group for gay and lesbians affected by MS: "GLAMS". We thought this could be an interesting idea for our organisation in Norway. The idea was presented to the Board of the Norwegian MS Society, and received a very positive response. The first challenge was to find people interested in taking part in the support group. Since only a few people responded to an article in our Society's newsletter, we contacted a magazine for gay people in Norway and asked them to publish an article about our initiative, and in February 2004, a two-page article was published. The article featured a woman with MS, the Norwegian MS Society and the aims of the new support group. This generated greater interest and we heard from more people who wanted to participate.

The Norwegian MS Society arranged the first meeting for the support group in April 2004. The meeting was held in a restaurant, and six people attended. Last year we organised four meetings and membership has increased to 12 (two men and ten women). Finding a name for the network was simple: LeHoMS (Le (lesbian) – Ho (homosexual) – MS). At the first meeting, we discussed why the creation of the group was important. Some people outside the

# MS Society of Norway: Support group for lesbians and gay men with multiple sclerosis

By Turid Hesselberg, Social Worker, Norwegian MS Society

group could not understand why we wanted to create it. Although the acceptance of homosexuality has improved in recent years, there are still a number of sceptics. Since 1993, gay men and lesbians have been able to formalise their relationships legally in Norway, but it is evident that some people are afraid of diversity and may have irrational feelings. Nevertheless, the group grew in strength and purpose.

An article published in Norway in 2001 about disabled and gay men and lesbians brought up challenges for LeHoMS. It motivated the members of LeHoMS to formulate a list of arguments to support the importance of a network that meets the diverse needs of gay men and lesbians with MS. They are listed here:

- Physical impairment and fatigue make it difficult for people with MS to go to public meeting places such as bars, clubs and restaurants.
- Often, typical meeting places are inaccessible for people using wheelchairs.
- Access limitations make it difficult to initiate and maintain friendships and intimate relationships.
- Negative feelings about one's own body image are a barrier to meeting new people.

- Many people face the double stigma of being disabled and gay or lesbian.
- Many gay men and lesbians with MS and other impairments experience loneliness and social isolation.
- Negative attitudes of health professionals create additional barriers.

Members of LeHoMS agree that it is positive to share these joint concerns. It is not necessary to talk about being gay, since this is one of the criteria for participation. This gives members the opportunity to talk about MS and life without sexuality as a predominating theme.

The group has a number of initiatives in the planning phase, including a brochure and seminars. The hope is to plan a meeting with the GLAMS group in England in the future so that we can create an international exchange of experience and ideas.

LeHoMS would be interested in hearing from groups in other countries, or from individuals who are interested in starting a group in their own country. Contact Turid Hesselberg, tel +47 2296 3586 Wednesdays and Fridays, or by email: turid@ms.no

# Results of the MSIF online survey on relationships, intimacy, sexuality

Responses to an online survey on the MSIF website ([www.msif.org](http://www.msif.org)) have revealed what some of our online readers think about sexuality and MS. Three hundred and sixty-six people with MS responded, of which 87 per cent currently have a sexual partner.

## This is what we learned:

### Impact of MS on the relationship

The results show that MS, or specific issues related to MS, have a significant influence on relationships. The box provides details on these MS-related issues. Fatigue, loss of libido and altered sensations were the most commonly reported factors influencing relationships.

### Changes in lifestyle/way of thinking

Over half of the respondents have made changes to their lifestyle or their way of thinking to maintain or enhance intimacy and sexuality. The study confirms that sexual difficulties are crucial in determining the way a person feels about him or herself as a man or woman, with almost two-thirds of respondents reporting that sexual issues have an impact on their view of themselves.

### Communication

Two-thirds of respondents experienced difficulty in communicating with others (either a partner, healthcare professionals or others) on MS-related sexual difficulties.

The survey revealed that fewer than a third of the respondents have benefited from counselling, advice and therapy, and almost two-thirds have had a negative experience with treatment for specific problems.

The results of the study confirm that for people with MS, disease-related issues, such as symptoms, have a relevant impact on relationships. Intimate problems are common and open communication is crucial to addressing sexuality and intimacy concerns, although not many people seek professional help or benefit from treatment for specific problems.

### MS-related issues influencing relationships

Fatigue	63%
Loss of libido	51%
Altered sensations	47%
Feeling less confident sexually	36%
Feeling less attractive	33%
Sensory disturbances	25%
Erectile problems	24%
Decreased vaginal lubrication	22%
Too many other problems to think about sex	20%
Bladder or bowel problems	19%
Feeling socially isolated	18%
Poor concentration	16%
Role changes/conflicts	12%
Managing catheters	3%
Cultural values create sexuality-inhibiting expectations and judgements	3%



# Quality of Life Principles

By Paul Rompani, MSIF

The Principles to Promote the Quality of Life of People with Multiple Sclerosis (Quality of Life Principles) is a new advocacy tool developed to help people affected by MS (eg MS societies and organisations). The aim of the Principles is to improve the quality of life (QOL) of people with MS.

The Principles are evidence-based international standards that focus on the common issues that affect the QOL of people with MS, for instance the distress and disability caused by the many symptoms of the disease, the inability in some cases to live at home, the loss of paid employment, the loss of mobility, and the lack of co-ordination between medical and social care. As a result, they are not linked to particular types or stages of MS.

The Principles are designed to be used by any individual, group or organisation involved in making decisions that will affect the QOL of people with MS. They will guide the development and evaluation of existing and proposed services and programmes, irrespective of the provider, and will help to advocate for improvements. Users include international organisations, governments, non-profit and for-profit health, social care and continuing care service providers, employers, national MS societies, researchers, businesses and, most importantly, people affected by MS.

MSIF is preparing three practical guides describing how the Principles can support MS Society programme planning, sharing best practice and influencing public policy.



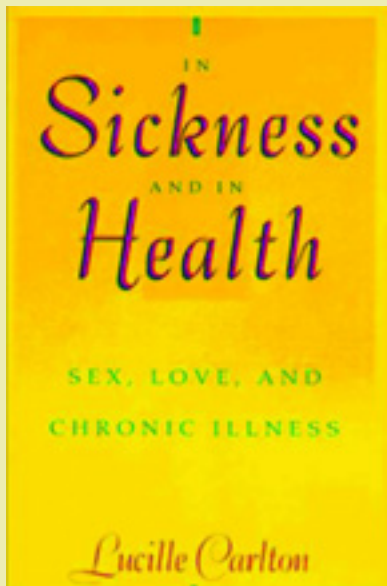
The development of the Principles was based on a series of interviews, a literature review, the clinical, programmatic, and research experience of the authors, and review by a Work Group and a technical Oversight Group organised by MSIF. The interviews were conducted with a range of international MS and QOL experts, MS clinical providers and people with MS, many of whom were from the UK.

# Reviews

## Book review: *In sickness and in health: Sex, love and chronic illness*

By Lucille Carlton

Review by *Cristina Gómez Ortiz, AEDEM, Spain*



The purpose of the book is to educate and inspire creativity in dealing with the sexual needs of couples of all ages living with chronic illness. It is written from the female point of view since the author is the wife of a Parkinson's

disease patient. Lucille Carlton was married for almost 50 years and had a very good marriage, maintaining sexual intimacy through two chronic illnesses. Her husband cared for her when she was debilitated for many years by a rare skin disease, and she cared for him through 16 years of Parkinson's disease. The information in the book is, therefore, applicable to many people dealing with various chronic illnesses.

The author gives examples of daily situations and feelings that people affected by chronic illness may experience in relation to intimacy and sexuality. She also talks about her own experiences in her marriage, as well as the experience she gained from working as a speaker and a columnist for the National Parkinson Foundation.

The ideas in this book are supplemented by the opinions and experiences of people with chronic disease and their partners, which help to make it

convincing and complete. While there is no “professional” opinion in the book, the diversity of the contributions from real experience makes this omission irrelevant.

The book is focused on people with a chronic illness, single or living in a couple. I would say that certain chapters of the book are pertinent for the general public, since sexuality and chronic illness are topics that often arouse fear, and a better understanding of people's experiences can benefit everyone. I think it is one of the best books that has been written for people with MS because it speaks openly about a topic that creates anxiety and apprehension for many, but which is relevant to all people living with a chronic illness.

The writer's style is simple and clear, which makes it very easy to read. The book had an important influence on me and I am sure that it could be useful to others.

*Publisher: Dell, 1997, ISBN: 0440508053, Price US\$9.50*

## Website review: *The Sexual Health Network website*

Review by *Tim Miller, Italy*

The Sexual Health Network website is an American commercial website covering a broad



range of illnesses and in the context of sexuality. As a point of access it can be helpful to those interested in aspects of MS and sexuality, with some pages specifically tailored to MS.

The site's mission-statement clearly describes its scope and purpose. It is an English-language website, access is free, no special software is required to view the information, and navigation is straightforward, although it would be helped by the inclusion of a site map. Information on the site's experts and their backgrounds are included, as well their photographs. Contributions to the site are fairly recent, although the frequency of updates is not clear. It is intended as a starting point from which to move on to counsellors and therapists and to other sites through web links, banners and pop-ups (see review below).

As a gateway to further information it contains links through to the Healthology website from where audio and video clips can be downloaded, as well as related texts.

It can be useful and an immediately available point of information. The validity of the help available and the links contained are a matter for the visitor to judge, as with all Internet resources. It is a valuable starting point.

<http://www.sexualhealth.com/>

### Website review: Healthology

*Review by Claudio Solaro, MD, Department of Neurology, Micone Hospital, Genoa, Italy*

This website is not MS-specific, although there is an MS section. It also covers neurological diseases and symptoms such as headache and dementia and non-neurological diseases such as tumours. Access to all parts of the site is free-of-charge.

With regard to the MS section, the site design is user-friendly and is easy to navigate, both within the main sections and between links. Many MS



issues are covered with up-to-date information, and the website is useful both for people with MS and specialists.

The audio/video sections are informative and can improve knowledge on management in clinical care for physicians, and also for other MS professionals. Some of the interactive options include courses that present various topics. This is a useful approach to get a quick readout about the state-of-the art on different MS issues. The contributions are from opinion-leaders in the MS field, whose knowledge and expertise is internationally acknowledged, lending a high level of authority to the site content.

While the site is very interactive, it is not possible to print some of the sections. A caveat regarding this site is that many sections need an audio system support programme (and audio speakers) that may not be easily accessible to all users. Moreover, the website is based on video sections that are not manageable in a simple way by Windows XP.

Overall the site is user-friendly and very informative. I would recommend it to healthcare professionals and anyone interested in learning more about MS and its treatment and management.

<http://www.healthology.com/focus>

# MS *in focus*



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MSIF is a non-profit charitable organization 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967. UK registered charity 1105321.

## Subscriptions

The Multiple Sclerosis International Federation produces **MS *in focus*** twice a year. With an international cross-cultural board, easily accessible language and free subscription, **MS *in focus*** is available to all those affected by MS worldwide. To subscribe, log on to [www.msif.org](http://www.msif.org)

## With many thanks

MSIF would like to thank Serono for their unrestricted grant which made the production of **MS *in focus*** possible



A new chapter has been added to the International MS Nurse Care Plan – a comprehensive and practical guide to the specialised field of MS nursing.

A group of world-renowned MS nurses convened in October 2004 to finalise it and ensure that it was developed in accordance with continuing medical education (CME)

regulations and free of commercial bias.

This new chapter is focused on Treatment Optimisation. The introduction of the newer disease-modifying therapies have heralded a new era in the management of relapsing MS. However, ensuring optimal medical and health outcomes for patients using these therapies depends on various factors, including:

- patient appropriateness for and readiness to initiate treatment
- treatment efficacy
- monitoring and management of possible side effects
- benefit-to-risk profile
- the patient's physical, cognitive, and psychosocial status

Since nurses are the main healthcare professionals to have day-to-day contact with patients, they play a pivotal role in identifying and overcoming problems and, thereby, help ensure optimal treatment outcomes. The new chapter outlines an evidence-based nursing approach that is designed to guide and assist nurses through this demanding and long-term process of treatment optimisation.

### **Maria Grazia Cali**

Serono Symposia International  
[www.seronosymposia.org](http://www.seronosymposia.org)