

Accelerated Cure Project for MS

May 2019

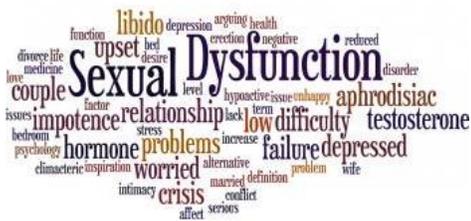


Live, Laugh and Love with MS

Intimacy is defined as “a close, familiar, and usually affectionate or loving personal relationship with another person.” It refers to all of the ways, both emotional and physical, in which partners connect and feel close to one another. The emotional aspect of intimacy involves trust, open and honest communication, shared goals and expectations, as well as mutual respect and concern. Physical intimacy is an act of sensual contact (touching) between people, such as hugging, kissing, or having a sexual relationship. Intimacy and sexuality are important components of a healthy and contented life. While MS may affect these important feelings, they do not have to disappear from the lives of couples when one or both partners have the disease. Whether one is newly diagnosed, physically disabled, young, mature, single or in a long-term relationship, partners can find satisfying ways to overcome any barriers to intimacy they may encounter.



Generally speaking, sexual function typically changes throughout an individual’s lifespan, however MS can have a compounding negative effect. Studies show sexual dysfunction (SD) is common in people living with the disease, affecting [40-80 percent of women](#) and [50-90 percent of men](#). The ways that MS can affect intimacy and sexuality can be divided into three categories: primary, secondary and tertiary SD. Sexual response and intimate feelings are mediated by the central nervous system (the brain and spinal cord). Sexual messages are communicated via nerve pathways between various sections of the brain, spinal cord and genitals throughout the response. Primary SD is caused by demyelination of these pathways. Since MS lesions may randomly occur along many of these nerves, it is not surprising that changes in sexual function are common. Women may struggle with decreased vaginal lubrication, and men may have erectile dysfunction. Examples of primary SD found in both genders may include loss of libido, changes in sensation, or difficulty achieving orgasm.



Secondary SD is caused by MS symptoms that do not directly involve nerve pathways to the reproductive system, but still have a negative impact on the sexual response. As discussed in our [March 2019 newsletter](#), fatigue is perhaps the most common symptom reported by people with MS, and it can be the most disabling. 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. Muscle weakness may necessitate alterations in sexual practices. Lack of coordination may make sex and sexual expression feel clumsy, as can tremor. Another possible source of anxiety and distress is bowel and bladder dysfunction. Incontinence, or even fear of having an accident, can cause a person to avoid sex entirely. Urinary tract infections are common in MS and are sometimes aggravated by sexual activity. Pain may significantly impact sex as well as performance ability. Medications used to relieve pain may add to sleepiness or fatigue. Changes in sensation can also interfere with sexual pleasure. Spontaneity may be a problem if mobility is an issue and asking for help is often difficult. Cognitive changes can also cause a problem in this regard. Changes in mood, memory loss and depression can be frightening, frustrating and sometimes aggravating. All interfere with intimacy.

Tertiary SD results from the emotional factors related to living with MS. The disease can alter a person's perception of him or herself as an individual and have a resulting negative impact on sexual and intimate functioning. In many ways, these feelings raise the most difficult barriers to intimacy, as they can affect both the person with MS and his or her partner. Cognitive issues have the potential to undermine a person's self-esteem. Altered attention and concentration may be perceived as lack of interest or love, and may strain a couple's relationship. Mobility devices, such as canes, wheelchairs, braces or walkers, can damage confidence and self-image. Tertiary SD may also stem from many other things, including depression, performance anxiety, or changes in family roles.

Although SD in people with MS often has a neurological cause, its evaluation is not always included in routine clinical practice. As a result, health professionals often miss important information and problems experienced by the individual with MS are left unaddressed. More often than not, the person with MS needs to bring up the subject, as most physicians don't routinely ask about it. Assessment and treatment of these problems is complicated, as there are many factors involved. An evaluation should include a full medical history, physical examination (including a pelvic exam for women) and laboratory testing to exclude contributing conditions, such as diabetes, high cholesterol and testosterone deficiency in men. Careful assessment of the impact of medications and substance use is also important. Because SD is multifactorial, it's important to work with one's healthcare team to manage other MS symptoms (physical, cognitive or emotional) that may be an underlying cause. Once these factors have been addressed, individuals can work with their healthcare team to identify the most effective treatment strategy for any primary SD that may exist. There are many therapies that can help once the subject has been raised, including medications, devices and other



alternatives. Not all treatments are successful for everyone, and individuals may need to work with their physician to find the right one.



As mentioned above, the majority of women with MS suffer from SD at some stage of the disease. The most commonly reported sexual problems in women are low desire, vaginal dryness, lack of sensation, difficulty with arousal, trouble reaching orgasm, and pain. [Estrogen creams or suppositories](#) may be useful for women experiencing vaginal dryness, pain or burning. Water-soluble lubricants, such as [K-Y Liquid](#) and [Astroglide](#) may also help with lubrication, as can [coconut oil](#). Medications such as [phenytoin](#) and [carbamazepine](#) may reduce discomfort or pain. Sensory changes like numbness, which sometimes occur in the vaginal area, can make intercourse uncomfortable or interfere with orgasm. Gently rubbing the genital area with a cold pack may reduce discomfort. Increasing stimulation to the genital area with oral or manual stimulation can help overcome numbness. [Kegel exercises](#) can help with muscle weakness in the vaginal area, and also enhance vaginal lubrication, arousal and satisfaction.

As discussed in our [June 2018 newsletter](#), SD is an issue that most men struggle with at some point in their lives, whether they have MS or not. As mentioned earlier, it is common in men with MS and may occur at any stage of the disease, even without severe disability. Erectile dysfunction (ED) is one of the most common symptoms of MS in men, affecting up to 91 percent. ED can be treated with oral medications, such as [Viagra](#), [Levitra](#), or [Cialis](#). As an alternative to oral ED drugs, injectable medications such as [alprostadil](#), [papaverine](#), and [phentolamine](#) can often enhance erection by increasing blood flow in the penis. In cases of severe ED in which other options have failed, [penile implants](#) can help. Between 35 and 50 percent of men with MS experience problems with ejaculation. These problems may include premature, delayed or [retrograde](#) ejaculation, or not being able to ejaculate at all. Although the treatments described above can help with ED, there are no medications that help with ejaculatory dysfunction. While a man's sexual performance may be improved by being able to maintain an erection for longer, ejaculation may remain a problem.



There are a number of strategies to help individuals struggling with secondary SD. In cases where fatigue is a problem, energy conservation is generally helpful throughout the day. These techniques can be applied to sexual issues as well. For example, time for intimacy can be prioritized for a time of day when the person with MS has the most energy. If medication side effects are suspected to be worsening fatigue, a schedule adjustment could provide relief. Dosing can be timed to allow for more energy when intimacy is planned. If weakness is a problem, fitness programs modified to work with a person's physical limitations may be helpful. Comfort measures, such as properly placed pillows, or different positions can also be used. For bowel and bladder dysfunction, limiting fluid intake for a few hours before sexual activity, or simply padding the bed can be effective. For men, leakage of small amounts of urine can be managed by wearing a condom. Another strategy is performing intermittent self-catheterization to empty the bladder completely prior to intimacy. If pain is an issue, an extra or well-timed dose of pain medication before intimacy may provide relief and reassure one's partner that he/she is not adding to any discomfort. As mentioned earlier, lubricants can make intercourse

more comfortable. A number of [sexual aids](#) can also be used to help with sensory issues, or simply to enhance intimacy in a relationship.

Open communication is key to resolving any problems with sexuality. In many cases, the biggest problem is the inability to discuss sex and intimacy with one's partner. Avoiding the subject can easily result in

How To Communicate More Effectively



misunderstandings, resentment, or stopping sex and other intimate contact. When changes to intimacy and sexual function occur, a reciprocal communication between partners about what feels good and what doesn't becomes crucial, particularly if intimate activities previously enjoyed together are no longer possible. Individuals who experience these problems need to allow themselves time to assess their overall situation and feel confident about communicating their difficulties to their partner. Deciding on a time and a peaceful setting to talk helps to create an atmosphere of mutual commitment. It is important to be gentle and express feelings without

blame or accusation. Couples should explore this sensitive subject slowly, listen to each other carefully, and respect each other's opinions. Writing down thoughts may help put the problems into language and start the difficult process of communicating. Couples may find confiding in each other actually deepens intimacy and may go a long way toward resolving fears.

It may also help to seek the advice of a health professional. Counseling can help individuals to explore their feelings and facilitate discussion in a respectful and professional way. Strategies for improving the situation, or adopting new ways of considering and developing sexuality, can be introduced. It is important to find an MS healthcare provider with whom one feels comfortable, preferably someone specializing in this area. Couples may find going together to be helpful, and pre-written questions may provide focus for the initial consultation. The National MS Society's [MS Navigators program](#) provides people affected by MS with the information, resources and support they need to address challenges like SD. The Society can also refer individuals to community-based [counseling services](#) in their area.

Sexuality is an important aspect of intimacy for most couples. When MS enters the picture, the best way to hold on to feelings of intimacy is for partners to function as a team, working together to adjust and adapt while making sure that any feelings of frustration are directed at the MS rather than each other. When shared expectations and dreams are threatened, partners can team up to identify "work-arounds" that allow them to pursue their shared goals and avoid blame and guilt. When living with MS, creativity, flexibility, and a good sense of humor are the key ingredients for making many things work, including problems with intimacy. Many couples living with the disease report that facing such challenges in this way has allowed them to connect with one another in new and powerful ways, finding an intimacy that was stronger than any they shared before.

