


Multiple
Sclerosis
Trust

MS

Sex & MS

a guide for

MEN



Simon Webster

We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

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Freephone 0800 032 3839 (Lines are open Monday – Friday 9am-5pm)

email infoteam@mstrust.org.uk

write MS Trust
Spirella Building
Letchworth Garden City
SG6 4ET

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Introduction

This book is written for men with MS who are worried about sexual issues and for those who may be sharing sexual activity with them.

It will discuss some of the complicated factors that contribute to and influence sex and some approaches that may help manage these.

Difficulty with erections, orgasms and having satisfying sex are not unusual. Studies estimate that 50-90% of men with MS will be affected by sexual issues to some degree at some time. Some difficulties may be long lasting or permanent whilst others may come and go. Although sexual concerns are more likely the longer someone has had MS, they can occur at any time, regardless of whether you are straight, gay or bi and whether part of a couple or single.

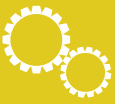
The popular view is that a man's sexual problems are usually due to difficulty with erections. This may be the most obvious physical symptom with some easily accessed treatments but sexual issues result from a complex interaction of different things - physical, social, psychological and emotional. Rarely are these solved simply with a pill.

Difficulties with sex, whether with a partner or on your own, can have a profound effect on health and well-being. Not being able to achieve sexual satisfaction can cause frustration, depression and a sense of loss, as well as loss of confidence, self-esteem and self-image that can affect more than just your sex life.



Many men find it awkward or embarrassing to talk about sex. Some men think their sexual symptoms must be an inevitable consequence of MS that has to be endured. Others might think that their difficulties are unrelated to MS and may feel guilty or shameful about what they are going through. Sexuality is an important part of life and factors that affect this, whether physical or emotional, should be taken seriously.

This book will not immediately solve sexual difficulties and cannot cover all of the complex issues that may be involved. Neither will it suggest ways in which men with MS might meet potential partners. However, by raising awareness of the treatments and advice that is available and ways of managing difficulties that may occur, we hope it will show you do not need to struggle in silence.



Sexual response - how it should work

The male sexual response can be divided into different phases

- sexual desire
- arousal
- orgasm and ejaculation
- afterwards

Sexual desire

Sexual desire or sex drive (libido) is the urge to engage in sexual activity. Although not properly understood, desire is thought to be a combination of psychological elements - including how you think of yourself, how you think about a partner, previous positive and negative experiences of sex, cultural and religious factors, your mood - together with physiological factors such as hormones, biochemistry and nerve activity in the brain.

Arousal

Sexual desire usually leads to physical arousal, the most obvious result of which is the erection of the penis.

Signals from the brain relax the blood vessels in the penis causing the spongy tissue in the shaft to fill with blood. This makes the penis swell and stiffen, which traps the blood and maintains the erection.

Erections can be caused by spontaneous signals within the autonomic nervous system - the section of the nervous system outside conscious control - which respond to physical stimulation such as touch. These erections tend to be short lasting. Erections that last long enough for sexual activity involve messages from the brain's response to erotic stimulation from sight and thought, such as sexual images, memories or imagining of sexual situations and, well, depending on your own preferences, pretty much anything.



Nocturnal erections and early morning erections are an automatic response not necessarily associated with erotic arousal. The presence or absence of nocturnal erections may indicate if problems in maintaining an erection are physical or emotional.

Orgasm and ejaculation

Orgasm is the climax of the sexual response cycle. In biological terms it is defined by muscular contractions in the lower pelvic muscles around the genitals and anus, accompanied by increased heart rate, blood pressure, and breathing. Beyond these responses, orgasms affect men in different ways and can be associated with feelings of relief, pleasure or euphoria, involuntary vocal noises, and sometimes muscular sensations or spasms around the body.

Ejaculation is the ejecting of semen from the penis in a series of about five to ten muscular contractions or spurts.

Although ejaculation and orgasm usually occur at the same time, they are separate processes. It is possible for a man to have an orgasm without ejaculation (dry orgasm) or to ejaculate without reaching orgasm. The occurrence of one without the other tends to result in a less satisfying sexual experience.

Afterwards

After sex, the blood trapped in the penis is released and the penis returns to its flaccid, non erect state.



Managing sexual issues

The arrival of Viagra (sildenafil citrate) in the late 1990s marked a shift in the way that treatments for sexual dysfunction were discussed. In the time since its launch, the drug has become a brand widely recognised by the general public.

In some ways this has been a liberating process. Men who might previously have been reluctant to discuss their symptoms in the belief that nothing could be done, now at least know the name and reputation of one of the drugs on the market that might help them. Through its absorption by popular culture, Viagra is seen, erroneously perhaps, in a positive light as a drug that enhances sexual performance rather than with the more negative connotations of being a treatment for medical symptom.

The downside of this familiarity is that it perhaps encourages the idea of male sexuality being solely about penetrative sex and performance, assumes that sexual problems are all about difficulty with erections, and promotes the misguided belief that sexual difficulties can be easily and solely treated with a pill.

For many people, sexual issues stem from a combination of physical, psychological, emotional and social factors. These fall into three broad groups arising:

- directly from MS damage to nerve pathways in the brain and spinal cord that process erotic stimuli, sexual feelings and responses
- indirectly from symptoms of MS, such as loss of sensation or spasm
- from the wider consequences of having MS, such as worries about work or finance or lowered self-esteem.



Effective treatment needs careful analysis of all the elements that are affecting the individual and then finding the right approach or combination of approaches to help address these. For example; if fatigue is affecting sexual performance, a pill that makes it easier to achieve an erection is not going to resolve the problem of physical stamina.

Similarly, medication alone won't resolve feelings of being unattractive or sexually less desirable that can come from living with a long-term and potentially disabling condition.

Medically restoring the ability to maintain an erection might mean that alternatives that are better suited to the man's abilities are overlooked or ignored. Rather than being concerned solely with the pursuit of erection and orgasm, more mutually caring and supportive approaches, for instance focussing on touch and sensuality, might be more fulfilling and rewarding.

Self medication

Some men, particularly those who are more reluctant to talk about how their sex life has been affected, may turn to the internet for help for their symptoms. This offers a degree of anonymity and also a wide array of potions, creams and devices that often make bold and unsupported promises. A great deal of caution needs to be exercised when considering these options. There is plenty of evidence of unscrupulous sites trading as online pharmacies and selling drugs of dubious quality and efficacy. For instance, in 2005 it was estimated that Viagra featured in up to one in four of all spam emails.

With all medication, there is a risk of interactions with other treatments, whether for MS symptoms or other conditions. When preparations are bought online, the levels of information and reliability of products can be greatly compromised. Despite glowing testimonials, it is not always clear



what a product actually contains and how this will affect other treatments. It is important for doctors prescribing medication to know what else you are taking. This applies to all types of treatments - prescription, over the counter, alternative and illicit - regardless of whether they are being used to treat MS or not.

It's not all MS

Of course, having MS doesn't stop you from experiencing sexual issues unrelated to the condition. Problems with erections and orgasms are relatively common in the general population and can be due to a number of non MS related causes.

- Lifestyle factors, such as drinking too much alcohol, taking drugs, obesity or smoking
- Other medical conditions, such as heart disease, diabetes, high blood pressure or kidney problems
- Psychological causes, such as anxiety, stress and depression
- Side effects of medication, such as some anti-depressants or anti-spasticity drugs
- Venous leak - a physical condition in which the extra blood in the penis is not retained during an erection
- Negative feelings about sexual situations, which might be due to personal beliefs or prejudices, or cultural or religious views
- Ageing - difficulties with erections are more frequent in older men

The cause of particular issues may involve several factors, some related to MS and others not. Effective management requires a thorough assessment of all the possible contributing issues.



Reduced sexual desire

Living with MS can have a profound impact on sex drive, undermining your sense of self, sexual identity and enjoyment, and your confidence as a sexual partner or potential partner.

For some this may cause occasional, temporary episodes when it is difficult to be motivated or interested in sex. For others it can result in a lasting reduction in sex drive.

My libido can alternate between extremes, from no interest to being my primary thought for days.

Seemingly small changes in lifestyle can have very uncomfortable and dispiriting effects that alter the way you perceive the world and how you think the world perceives you. Changes at work might mean you are earning less, possibly altering how you see your standing or making you feel you are not contributing your full share to the household. Physical changes might make you feel or be more dependent, even in relatively minor ways such as doing less driving or needing more time to rest. The way friends and family react can also chip away at confidence. Sometimes unknowingly, people can start to treat you as fragile or in need of looking after in a way that is out of proportion to actual or stated needs.



My ex was a nurse and too often sought to act in a 'nursing' fashion towards me. I was a stupidly stubbornly 'independent' man. This created tensions.

Living with the symptoms of MS might have a limiting effect on your social life, particularly those activities that had been enjoyed independently. Symptoms that require the use of a stick or a wheelchair, or more discreet interventions such as self-catheterising, can also have an effect on how you view yourself.

Sitting in a wheelchair I feel not just invisible (because I'm not at eye-level for most people and they look straight past me) but worse still, sexually invisible - a non-person as far as sex is concerned

When you feel bad about yourself and feel self-conscious about how you look to others, this will alter how you interact with people. It may make you feel isolated, less attractive, less 'manly'.

As my legs have gradually deteriorated, I have had a whole new process of 'coming out' to handle - coming out as disabled. This has dealt quite a blow to my feelings of confidence and sexiness.



Other sexual factors have an effect on desire. It is not always easy to tell if difficulty in getting an erection or in reaching a satisfactory orgasm result in reduced interest in sex, or waning sexual interest makes achieving these more difficult. Although often interrelated, the two issues don't always go together. Someone with an undiminished sex drive may find that their body doesn't respond as they want. Similarly, someone with little or no appetite for sex might still experience erections.

Erosion of self-confidence may make you worry that you are no longer fulfilling the required sexual role in a relationship, even in the absence of partners expressing discontent. Lacking the desire for sex may result in infrequent sexual activity which then can be less fulfilling when it does take place.

My sexual desire has reduced. I have fewer sexual thoughts and fewer erections. Orgasm and erection take much longer and require more effort! I find the physicality of sexual intercourse very difficult.

Issues unrelated to MS need to be considered when trying to find ways to manage a lack of interest in sex. Stress, anxiety and depression can all have an effect, as can worrying about things like work or finances. Physical factors such as hormone imbalance can also lower sex drive, as can alcohol or drug use.



Ideas for coping with some of the emotional effects of MS

Be positive

Negative thoughts about yourself as a sexual partner can result in a vicious circle - negative thoughts and feelings feeding off themselves and making problems appear worse than they really are.

Making changes and choices to challenge these feelings takes time and effort. It requires courage to face these issues and seek solutions. Expert guidance such as CBT (cognitive behavioural therapy) counselling can help challenge negative thoughts, feelings and behaviours and help to find new, positive ways of managing. The cycle can be reversed.

If you feel yourself to be sexually unattractive, it may be more to do with what your mind tells you than what your body can do

Look after yourself

In the same way that facing the world with a positive outlook can help, so can taking care of your outward appearance. It can be a struggle to get up, dressed and groomed for the day ahead but making that effort to look good can help you challenge negative feelings of lack of confidence or self-worth.

I tell myself I can look cool with the right walking sticks or scooter!



Stay social

If MS is sapping your confidence, it can be tempting to shut yourself off from the world - particularly if relationships suffer setbacks. Sometimes we like to hang on to our anger and disappointment. Meeting other people helps to keep difficulties in proportion.

Keep in regular contact with friends - in person, by phone, online. If you find it difficult to get out regularly or symptoms make social settings difficult, invite people to your home or somewhere where you feel more comfortable. If your circle of friends has shrunk, consider ways to meet new people, such as adult education classes or volunteering within your community. If you are looking for a partner, dating websites offer a way to get to know people that doesn't rely on appearance. Getting to know someone online may help you build up confidence before arranging a face to face meeting.

My new girlfriend appears to have accepted me as I am and has said that she was attracted to my determination in ploughing around music festivals last summer in my chair. It shocked me to think of the chair as part of the package of the attraction rather than a big negative.

Stay active

Staying as active as circumstances allow is vital to good health and has a role in reducing stress and low mood and counteracting the effects of fatigue. This need not mean following an exercise regime or taking up a sport - although the MS Trust has resources to help if this is what you want to do. Activities and interests such as gardening, photography or fishing that get you out and about can equally help you to feel better about yourself.



Remember your strengths

Although MS may have affected some of the things you can do, think of things that you like about yourself and what you see as your strengths. There may be new strengths that have arisen from living with MS, such as resilience, adaptability or sense of humour.

It is really how MS is handled by the individual to let one's personality shine through and not the MS.

Sexually this is important too. It is not always what you do, but how you do it. If certain activities or positions are difficult or no longer pleasurable, find out what does work and concentrate on that. And consider your partner's needs - what do they like and how can you achieve this?

It's not all about orgasm

Expressing love, affection, intimacy and sensuality do not depend on penetrative sex and the relentless quest for orgasm. Try to enjoy the process, exploring sensuality and touch, without being distracted by the need to reach climax. This applies equally whether or not you are with a partner.

Much less emphasis on intercourse or on orgasm now. Lots more touching.

Taking the focus away from sex itself is an approach sometimes used by sex therapists. Concentration on intercourse can sometimes blind people to the closeness and companionship that is an essential part of a relationship and the mechanics of sexual dysfunction can get in the way of the romance that brings people together.



Simple closeness, such as holding hands or cuddling and enjoying each other's company are vital to a relationship and can reassure both partners that they are the object of affection. This distance can help the couple to reassess what is important to their relationship and also consider their erotic and sexual likes and dislikes without the pressure to try to instantly act them out. This can lead to new routes into sexuality and help you to explore ways to achieve this.

My girlfriend and I enjoy a very good and active sex life whilst only infrequently getting penetrative. Foreplay need not just be foreplay and oral sex can be quite fantastic for both parties, without any erections getting in the way.



Erectile dysfunction

Erectile dysfunction, sometimes called impotence or ED, is the inability to achieve or maintain an erection.

It is estimated that nearly one in five men in the general population is affected at some point, either every now and again or more consistently over a prolonged period of time. Erectile dysfunction is thought to be more prevalent amongst men with MS and research suggests anything from one quarter to two thirds of men with MS are affected.

There are a number of possible causes for erectile dysfunction in MS.

MS nerve damage

Arousal and erection require a complicated interaction of nerve messages. When MS damages these nerve pathways, messages from the brain can be delayed or prevented meaning that arousal is not maintained or, in some cases, may not occur at all.

What can be frustrating is that a nocturnal or waking erection, which is not triggered by the brain's response to erotic stimuli, can still occur but doesn't last for long enough to be useful.

Other MS symptoms

Several MS symptoms can make it difficult to achieve or maintain an erection. If you experience pain or numbness in the genital area, potentially pleasurable sensations can become uncomfortable. Depression or reduced attention span or concentration can lead to distraction.

Fear of symptoms can also play a role, for example worry that sexual activity will provoke spasms or an episode of fatigue. Similarly being anxious about wetting or soiling yourself might inhibit anticipation and pleasure.



Emotional or psychological issues

As mentioned in the section on sexual desire, if MS has dented your self-confidence or self-image, or affected how you think partners see you, this may undermine your ability to enjoy sex and make erections harder to maintain.

Viagra solves half the problem but there is no treatment available to enhance feelings. If there were something, ejaculations would be easier

Managing erectile dysfunction

Although there are treatments available that can restore the ability to achieve an erection, the effective management of the symptom requires an assessment of the whole person, not merely their penis.

With this wider context in mind, the following treatments should be seen as part of the treatment of symptoms, not a complete solution in their own right.

Medication

Erectile dysfunction can be treated with a class of drugs known as PDE5-inhibitors - Viagra, Levitra and Cialis. PDE5 (phosphodiesterase type 5) is an enzyme that regulates blood flow in the penis. Altering levels of this enzyme means that normal sexual stimulation leads to better erections. Contrary to the many jokes, the use of these tablets without sexual stimulation will not cause an erection.

Multiple sclerosis is listed in NHS guidelines as one of the conditions for which erectile dysfunction drugs can be prescribed. The guidance says 'one tablet per week is considered to be appropriate for the majority of patients, but when more is required the GP should prescribe that quantity at NHS cost'. You do not have to be in a relationship to be given a prescription.



How you use your medication most effectively needs careful thought. If the prescription allows for one chance of sex a week, the level of expectation can lead to stress that works against feelings of relaxation and sensuality and potentially lead to disappointment and frustration. Within a relationship, if taken without planning, the opportunity for the man with MS to have sex may occur when the partner isn't in the mood, making intercourse seem functional, imposed or unsatisfying. Whilst the drugs can provide the ability to have penetrative sex, they don't of themselves create the anticipation and pleasure of sex.

All of the drugs have similar side effects, which include headaches, flushing, upset stomach, visual disorders, nasal congestion and dizziness. None of these drugs should be taken by people receiving treatment with drugs containing nitrates, such as are used to treat angina. They must be used with caution by people with existing heart conditions or problems with liver or kidney function or low blood pressure.

I know that this is bold-printed on the info with the tablets, but some (such as myself) might be tempted to continue trying to increase dosage over time as effectiveness is reduced by the progression of MS. I stupidly did this for some months late last year, and suffered from diplopia and nystagmus for several months as a result. Don't do it, kids!!

Viagra (sildenafil citrate)

Viagra was the first drug to become available as a treatment for erectile dysfunction, being licensed in 1998. Originally tested as a treatment for heart problems, it has also been used in treating high blood pressure (under the name Revatio) and, more recently, altitude sickness.

Viagra is taken about 30 minutes to an hour before sexual activity and the effects last for about four hours. It will take longer for the drug to take effect if taken after eating fatty foods or alcohol.



Several studies have looked at the effect of Viagra on men with MS with differing results. In one study, researchers compared 104 men taking Viagra with 113 on an inactive placebo and found that almost all of the treatment group reported improved erections. A second study with 101 men receiving Viagra and 102 on a placebo showed a less clear cut result, with only a third of the treatment group reporting improved erections.

Levitra (vardenafil)

Levitra is taken an hour before sexual activity and no more than once a day. The effects last for about four hours. A soluble tablet version is also available. As with Viagra, it will take longer for Levitra to take effect if it is taken with food.

Although there have been more general studies, there has been no published research into the effects of Levitra in men with MS.

Cialis (tadalafil)

Cialis is taken at least half an hour before sexual activity, though is most effective about two hours after it is taken. People who anticipate needing treatment more than once a week can be prescribed a smaller daily dose. This continuous dose must be regularly reviewed.

Cialis lasts longer than the other drugs. Some people may still experience effects up to 36 hours after use, which allows greater scope for spontaneity in lovemaking. Unlike Viagra and Levitra, the effects of Cialis are not delayed if taken soon after a fatty meal.

There has been one study of Cialis in multiple sclerosis in which men took the drug for eight weeks. Results showed it to be an effective and safe treatment for erectile dysfunction.



Other treatments

If the first line drugs are not effective, there are other approaches that can be tried.

Alprostadil (Caverject, Viridal Duo) and MUSE

Alprostadil is a synthetic form of prostaglandin, a naturally occurring chemical in the body that increases blood flow by relaxing muscle cells.

Alprostadil is applied directly to the penis by injection (under the trade names Caverject or Viridal Duo). Alternatively, a pellet can be inserted with an applicator into the tip of the penis (known as MUSE - medicated urethral system for erections).

Unlike the previously mentioned drugs, both methods of application of alprostadil will cause an erection without sexual arousal, lasting for about 30 minutes to an hour. This happens almost immediately with Caverject or after a few minutes with Viridal Duo. With MUSE, once the pellet has been inserted, it is necessary to massage the penis for a few seconds to help distribute the drug. This process can involve a partner and be part of foreplay. Whilst waiting for the drug to have its effect, which happens in five to ten minutes, it is important to remain upright as this helps blood flow to the penis. Lying down in this period will mean the drug is less likely to be effective. MUSE is also less effective if you use a catheter.

Side effects of Caverject and Viridal Duo can include pain in the penis or groin and bleeding in the tissue around the injection site. Less frequently, the erection may not subside for several hours, known as priapism. This can be uncomfortable and without medical attention may result in tissue damage in the penis.

A side effect with MUSE is a burning feeling or irritation at the end of the penis. The partner may also experience similar pain after penetrative sex and oral sex should be avoided with a man using MUSE. MUSE shouldn't be used if the partner is pregnant.



Vacuum constriction devices (VCDs)

A vacuum constriction device works by trapping blood in the penis. The penis is inserted into a tube and the surrounding air pumped out. This draws blood into the penis causing an erection. A tight band is placed around the base of the penis, trapping the blood and maintaining the erection. The band can safely stay in place for up to 30 minutes.

On first using a vacuum pump, the penis can feel cold. This can be countered by applying a warm lubricant or using in the shower or bath. Some men can feel pain or numbness in the penis or find they have a delayed or unsatisfactory ejaculation.

Although effective, devices can be cumbersome to use and take five to ten minutes to operate. Some people might find this to be intrusive and work against spontaneity, particularly for men who are not in a stable relationship. But for some it can be sexy and incorporated into foreplay. There are no rules.

Apomorphine (Uprima, Ixense)

Apomorphine is an injected drug used in the treatment of Parkinson's disease. In the treatment of erectile dysfunction, it works by stimulating chemicals in the brain which are believed to enhance the sexual response and to initiate an erection. Although there is no specific research in MS, general studies have shown that apomorphine is less effective than Viagra.

Side effects can include thickening of the skin at the injection site, sleepiness, nausea and vomiting. The drug must not be used by people with respiratory problems or with liver problems, and must be used with caution by people with existing heart conditions or problems with kidney function. Unlike the three PDE5-inhibitor drugs, apomorphine can be used by people receiving nitrates to treat angina.



Prosthesis

If no other methods are effective, there are different types of surgical implant that can mechanically assist with erections. One uses pouches that are filled with fluid to stiffen the penis. Another involves flexible rods that can be adjusted into the desired position. As both devices artificially stiffen the penis the result may not be as firm as a natural erection. Prosthesis is usually only considered when other options have not been successful.

Delayed or absent orgasms and ejaculation



Ejaculation difficulties are relatively common in the general population, with as many as one in three men affected at some point in their life, most frequently by premature ejaculation.

Men whose sexual performance is affected by MS are more likely to experience difficulty or inability in reaching climax, even though their erection is unaffected.

Ejaculation takes longer than before because of lack of sensation in the penis. My sex drive has not decreased at all, it has always been high.

There are a number of possible causes for this. MS can cause nerve messages in the spinal cord to be interrupted or blocked, making ejaculation more difficult. Reduced concentration, pain, numbness or fatigue, can make it more difficult to reach the threshold of stimulation at which orgasm and ejaculation occur.

I have greatly reduced sensitivity in my penis, which means orgasms can sometimes be difficult to reach, even by masturbation.

Understanding how these symptoms affect sex may also lead to ways to work around them. For instance, planning sex for times of day when fatigue or concentration tend to be less of an issue or exploring positions that are less painful to maintain.

Delayed ejaculation can also be due to psychological issues. These concerns may relate to MS and its effect on self-image, though other unrelated worries can also be to blame.



Anxiety about performance and the focus on orgasm as the culmination of sexual activity can have a negative effect - particularly if there is previous experience of not reaching climax. Seeing sex less as a functional process based solely on penetration and orgasm and more as a pleasurable, sensual experience can reduce these anxieties.

The quality and power of my orgasms has definitely diminished. I still feel my orgasms, and they're still fun, but they no longer flood me with the sort of euphoria I got when I was younger and fitter. This is disappointing, but there's more to sex than the climax, so it's not a huge loss - there's plenty else about sex still left to enjoy.

Managing difficulties with ejaculation and orgasm

Masturbation

Some men find it easier to reach orgasm with masturbation, whether from themselves or from a partner. If there is numbness or reduced sensation in the penis, masturbation can allow for more control of sensation, tightness and speed than intercourse. It is possible to have too much of a good thing. Some people find that reducing or stopping masturbation between sexual encounters can sometimes help them reach orgasm with a partner.

I masturbate and use baby oil. Now I am an expert in this craft and enjoy it to the full. Sometimes it is easier for me to masturbate because I can control the penis pressure and leg movement.

Vibration devices

Some people find that sex toys and vibration devices are helpful. Applied to the penis or scrotum, a vibrator can intensify sensual feelings and may be enough to help you reach orgasm. The more powerful the vibrator the more effective it will be. If you have a partner, finding toys that you both enjoy is important and can add a new aspect to your lovemaking.



My girlfriend and I have a good few toys between us, and these open up a space of 'play', making everything that bit more fun.

Anal stimulation

Some men find anal stimulation helps them to reach orgasm, although others may find this painful or distasteful. The anus has many nerve endings, so touching this area can create pleasurable feelings. Stimulation of the prostate gland can also heighten sexual feelings. The prostate lies just below the bladder and rests against the wall of the rectum. A well lubricated finger, penis or sex toy inserted into the anus can rub against this and can help lead to an orgasm for some people.

No treatments are licensed in the UK for ejaculation difficulties. There are treatments that have been reported to have some effect, but these have not been studied in MS and are not widely available within the NHS.

Midodrine

Midodrine has been studied in men with spinal injuries. Of 158 men with ejaculation problems, 65% did achieve ejaculation when taking midodrine.

Yohimbine

Anecdotally the herbal extract yohimbine has been thought of as an aphrodisiac and non pharmaceutical preparations are sold for this effect. It is thought that, when taken an hour or two before intercourse, yohimbine increases blood flow in the genitals and thus erotic sensitivity for some people. High doses can cause increases in blood pressure, anxiety and the need to urinate. There is little research into the preparation.



The effect of other MS symptoms

The effects of, or worries about, other MS symptoms can affect sex for some men. It is important that each symptom be fully assessed so that all factors contributing to sexual difficulties are understood. Without this understanding, treatment will only be addressing part of the issue and thus will be less effective.

The management of individual symptoms is discussed in other MS Trust publications (see the Resources section for details). This section looks at managing symptoms in relation to their effect on sex.

Fatigue

Fatigue is one of the commonest symptoms of MS. The key principles of managing fatigue involve maximising energy and planning how to use it to best effect. This applies equally to sex as to other aspect of life.

If you try to have sex when exhausted, it is likely to be less enjoyable. Knowing when and how fatigue affects you will help. Working out when fatigue is less of an issue will mean sexual activity is more likely to be satisfying. For instance, having a rest during the day before sex and allowing plenty of post coital recovery time afterwards can work wonders.

Physically there is the issue of being able to maintain certain postures and positions during sex. I do find some positions hard to maintain, and have had to make adjustments to accommodate this difficulty.

If you have a partner, talking to them about how fatigue affects you is important. They will be less likely to feel responsible for any lack of sexual response and can work with you to find different ways to cope with



reduced energy levels. This could involve creating new, sexy, intimate time when fatigue is less likely to be an issue or experimenting with different positions and different environments to find something that is less tiring. If full penetrative sex is not possible, less physically demanding approaches such as masturbation or oral sex may be more rewarding.

Weakness

Weakness can be associated with fatigue. If muscles are weak, movement requires increased effort which leads to additional fatigue. Weakness may make some positions difficult to maintain or achieve. A physiotherapist may be able to offer suggestions on sexual positions that take account of weakness. Experimenting with partners playing a more active or dominant role may reduce the impact of weakness and can be adventurous and fun.

It didn't take us long to realise that hauling me on top of her for me to wriggle desperately for a while just left the two of us exhausted and frustratingly unsatisfied. We soon saw it was so much better for me to take the passive role, at least physically, while she straddled me.

Spasticity and spasms

Some men with MS find that sexual activity, and orgasm in particular, can trigger spasms. This can be physically painful and sometimes embarrassing or upsetting. If you are prone to spasms, the fear of them happening can be a turn off and result in being tense and over cautious, or even avoiding sex altogether. Anti-spasticity medication can help, although a possible side effect of some of these drugs is to affect sexual function.

I tend to get cramps, especially when I reach orgasm, which can lead to some comical scenarios. From behind I can hold my legs firm but my left leg tends to go into spasm before I come to an orgasm.



Spasticity that limits the range of movement of arms or legs can make some sexual positions difficult. Experiment with different positions and ways of supporting arms or legs that are comfortable but still allow a range of movement and try to identify and avoid the ones that trigger spasms. For example, if lying flat on your back causes difficulties, use a pillow or a rolled up towel under the knees, bottom or the small of the back to break up spasticity and reduce the risk of spasms.

Relaxation before sex can help to reduce the risk of spasms. This might include a relaxation technique, gentle massage or limb exercise, all of which can be part of pleasurable foreplay.

When I perform the stretches my physio suggested prior to sex, I find that the spasms are much reduced. I have severe spasticity in my legs so finding a sexual position that doesn't trigger a spastic episode is difficult. I take a Valium about an hour before.

Continence

Worrying about wetting yourself can be a sexual turn off. Going to the toilet before sex can help with this. If self-catheterisation is required it might feel as if spontaneity is being taken away. However, knowing that your bladder has been emptied can make you feel more relaxed and ease the worry.

An indwelling catheter does not need to inhibit sexual activity and can be folded along the shaft of the penis and held in place with tape or a condom during intercourse. There may be self-image issues associated with a suprapubic catheter, but it does not get in the way of sex as the catheter passes through the wall of the stomach and there is no obstruction in the penis.

Concerns about soiling yourself can be managed by going to the toilet before sex, using a microenema if necessary. If this isn't possible or if continence remains an issue, a temporary anal plug can be used.



I always make sure I haven't wet myself before stripping off.

Pain

MS can cause a range of sensations from persistently uncomfortable feelings such as pins and needles or crawling, burning feelings, to more acute stabbing pains or persistent aches. This can make it uncomfortable to be touched in some parts of the body.

Body mapping, or sensate focussing, is a simple technique that can help you find areas of your body where pain won't get in the way of sexual pleasure. Body mapping involves exploring the body with touch to find which areas give pleasure and which cause discomfort. Mapping is not limited to areas commonly associated with sexual pleasure but should cover the whole body and use different textures and sensations that excite. Body mapping can be done on your own or with partners. The process is, of course, not limited to the person with MS and exciting ideas can be shared by exploring each other.

Finding just the right position during sex can be tricky, and sometimes comical, as I try to avoid those positions where my leg starts banging away rhythmically, or my calf muscles or thigh muscles go into agonising and passion-killing cramps.

These problems are easily overcome with practice and experience, and I'm enjoying working on it.

Low mood and depression

MS can have a profound effect on mood. This can occur both as a direct symptom of MS and as a reaction to all that living with MS brings. Depression dampens sexual interest and inhibits arousal so it is important that the effects of low mood are considered when assessing sexual issues.



There is a range of medications to treat depression although some can affect sex. The side effects of SSRI drugs (selective serotonin-reuptake inhibitors) such as fluoxetine (Prozac) and paroxetine (Seroxat) include absent or delayed ejaculation and orgasm and they may also reduce sexual desire and arousal. If this is the case, treatment with non SSRI antidepressants such as amitriptyline or imipramine, or non drug approaches such as CBT (cognitive behavioural therapy) may be worth exploring. Suddenly stopping treatment with anti-depressants can cause withdrawal symptoms, so talk to your doctor or MS nurse about gradually reducing doses.



Talking about sexual issues

Whether or not you are in a relationship, difficulty in satisfying your sexual needs can be a cause of frustration, disappointment and distress. The most important and most powerful starting point for managing sexual issues is to be willing to talk about them. Talk to someone with whom you feel safe and comfortable; it may be your partner, a friend or a health professional such as your GP or MS nurse. It may be anonymously via a helpline or chat room.

Talking to partners

If you are in a relationship, making sure your partner understands they are not the source of sexual difficulties can be a great relief to everyone. Without this understanding, they might interpret changes in desire or arousal as a reflection on themselves - a sign of waning affection or your loss of interest in them sexually - rather than a physical consequence of MS. If issues are not discussed, this can lead to cracks in the relationship that might be irreparable by the time help is eventually sought.

The chance of successfully managing issues is improved when partners are involved. Communication is vital and helps in adjusting and adapting to treatments that can require a more planned, less spontaneous approach to sex. If partners know what is happening and why, it allows for sex to be enjoyed when you both want.

Talking to my partner is the life saver - she is loving and understanding. And when I can stay awake long enough, I love stroking her hair and ears - and she loves it too.

telephone 0800 032 3839



When entering a new relationship, we all want to make a good impression. You may feel reluctant to admit to anything that you feel might undermine your attractiveness and a discussion about sexual dysfunction may not seem to be a persuasive chat up line. Whilst not mentioning difficulties with sex may succeed in the short-term, over time issues will become apparent and may lead to disappointment and conflict.

Talking to professionals

Although broaching the subject of sex with health professionals can be really difficult for some men with MS, sexuality is an important part of life and issues that affect this should be taken as seriously as any other MS symptoms.

All health professionals should understand that MS frequently enough has an impact upon sexual activity, so don't be shy! If they don't, it is their failing and not yours

A healthy approach is to be as open about sexual issues as you would about any other MS symptom. Once the initial hurdle has been passed it becomes much easier to talk about these issues. If the health professional you talk to isn't well informed or skilled at dealing with this topic, they should be able refer you to someone who is. If they don't, then you can ask for a referral to someone better able to help you.

There are people within the health service with expertise in managing sexual issues and who are used to these sorts of conversations. Most GP surgeries have access to someone with experience; it may be one of the GPs or the practice nurse. MS specialist nurses and therapists are aware of the sexual issues associated with MS and can provide advice or an appropriate referral. Continence nurses are also familiar with sexual issues and urology specialist nurses are skilled in managing both continence and male sexual problems.



Some ideas for raising the subject of sex

Ideas from men with MS

“Doctor, I’d like your help. I’m having problems with x, could it be my MS?”

I start by apologising for bringing the subject up. This seems to give me permission to talk about it and it then becomes much easier

I favour the direct approach - something like “Sex just isn’t what it used to be” something that compares before with now

Ideas from health professionals

Take a list of issues to an appointment and include any sexual difficulties. Either read the list or hand it to the health professional

Raise sexual issues during a general discussion about bladder or bowel symptoms. These may be easier to talk about and they are often related

An explicit statement like “I am having problems with my sexual relationship” or “I am having sexual difficulties” will help the professional more than vague statements like “my partner is disappointed with me”

For some, counselling can help. There are a limited number of psychosexual counsellors within the NHS who can offer specialised help, although more general counselling services can help address issues within relationships and find ways to face difficulties together. The College of Sexual and Relationship Therapists (COSRT) has a list of therapists and the Sexual Advice Association has a professionally staffed helpline service (see Resources section).



The partner's perspective

Being the partner of a man with MS has its own challenges. A diagnosis of MS changes not only the life of the person with the condition but also the lives of those around him.

Whilst not experiencing the symptoms directly, partners are affected by the impact of symptoms in many ways - lifestyle, employment, friends, etc. Partners can also experience their own feelings of grief, frustration and doubt. The life previously envisaged may no longer be attainable and the future can look uncertain. The frustration and uncertainty of living with MS can sometimes make people angry or irritable and difficult to be around. Unpleasant though they might be, these feelings are entirely normal and people are not alone in feeling this way.

I think that partners should know that it is natural that they too should grieve for what has gone and won't come back. If you do feel bitter and resentful, sometimes it's better to acknowledge those feelings and not beat yourself up for having them.

MS can alter the balance of a relationship. In coping with his symptoms a man with MS may become less self-sufficient and more dependent, less self-assured or less positive in outlook. It is possible for a relationship to move gradually from one of partnership to one of carer and cared for.

MS can have a profound effect on the way a couple views each other sexually. If a man with MS is unwilling or unable to have sex, it is easy for partners to feel frustrated or unfulfilled, to feel rejected or unloved and that they are the problem. There may be physical



changes in adapting to symptoms that result in certain positions being difficult or uncomfortable, or treatments that limit spontaneity.

It is important for partners to look after themselves too, both in terms of staying fit and well, and being aware of the impact of MS on their own confidence and self-image.

My wife attended a style day a few years ago. It improved her confidence in many ways and she now dresses much more attractively. She has taken up belly dancing, once again increasing her feelings of confidence and attractiveness. I enjoy encouraging her in these aspects.

If someone is living with sexual difficulties, there is a danger that it might rob a relationship of intimacy. The focus can become a process of attempting to overcome the man's problems rather than a shared process of pleasure and sensuality. If sex becomes solely based around the timing of medication or the use of devices, the experience will become functional and unsatisfying for both partners. Men with MS should not forget that their partner has their own sexual needs.

Don't forget that your partner needs attention and wooing and isn't up for it just because you are.

When he was using Viagra, sex wasn't spontaneous anymore - you had to plan in advance, which just didn't seem right.

Many people find that working through difficulties together can bring them closer and strengthens their relationship. Talking about the physical issues and being open about emotional responses of both partners can help lessen resentments that build up and create a shared challenge faced together rather than repressed, resented private wars. Rather than being stuck behind the brick wall of what can't be done, men with MS and

telephone 0800 032 3839



their partners can look for opportunities to explore other forms of intimacy - touch, sex toys, oral sex - and adventures in seeking satisfying ways of making the most of what is possible.

She is incredibly supportive. This huge change in our lives has strengthened us both emotionally and has brought us even closer together.

Sometimes professional help can be valuable and relationship or sexual counselling can offer a way forward. There are professionals whose job it is to help people facing these issues, so don't be afraid to ask.



Thoughts on sex from men with MS

Some men may think that MS has ended sex for them, but that doesn't have to be the case. I now have greatly reduced feeling in my penis and reduced muscle control, but I still enjoy an active and pleasurable sex life. This has required my partner and me to be adaptable and emotionally flexible, but we have both benefited from the changes we have made.

When getting in the mood, our favourite technique is to read an erotic short story together. Others may prefer role-play and dressing up, watching something sexy, looking at photos that arouse both of you, BDSM etc. Whatever works for you. You might find hardcore porn and large phallic vibrators arousing, but don't fall into the trap of assuming your partner will too. Let her choose, you may be surprised.

The Web can be a rich source of ideas. Many of the sites may just contain photos of scantily clad young ladies, but there are others that can be much more inspirational to both of you. Our favourite is the Erotica Readers and Writers Association, a site that contains a large number of erotic short stories as well as many other aspects of sex that you could find useful.

Sex required us to make adaptations to our techniques. As I became less mobile, we soon saw it was so much better for me to take the passive role. But this has meant we have found new skills and pleasures that we wouldn't have tried otherwise.

Sex has now lost its spontaneity and natural variety, and the frequency is considerably reduced. But I still have sex and enjoy having sex - it's just that good sex may now need careful planning.



I think about sex far less often than I used to. I don't have the strength and energy to play an active part in sexual intercourse and I worry about starting something I won't be able to finish. My partner is wonderful, lovely and sexy and I still have a sense that we are active lifelong lovers. We don't have full-blooded sexual encounters and our sexual touching is muted but we kiss and hold each other, we stroke and talk and laugh. And I feel hugely grateful for that.

Is sex like it was before MS? No, definitely not. Is sex still enjoyable? Yes, it can be. It may need more planning and recovery time, and the windows of opportunity may be narrower, but it's still fun. Enjoy what you have, and try not to dwell on the past. Be honest with yourself about what you can and can't do. Seek help if needed and take help if offered. Be honest and open with your partner too and be open-minded to their ideas - you might be pleasantly surprised.



Resources and links

College of Sexual and Relationship Therapists (COSRT)

Formerly the British Association for Sexual and Relationship Therapy

A charity whose members provide sexual and relationship therapy.

Tel: 0208 543 2707

email: info@cosrt.org.uk

Web: www.cosrt.org.uk

Sexual Advice Association

Formerly the Sexual Dysfunction Association

A charity providing advice on male and female sexual problems.

Helpline is open Monday, Wednesday, Friday from 9am to 5pm.

Tel: 0207 486 7262

email: info@sexualadviceassociation.co.uk

Web: www.sexualadviceassociation.co.uk

Sex and Disability Helpline

Professionally staffed helpline provided by the Outsiders Club - a self-help group for people with physical and social disabilities that affect sex and relationships. The Helpline is open weekdays 11am to 7pm

Post: Dr Tuppy Owens
BCM Box Lovely
London WC1N 3XX.

Please send a stamped addressed envelope with your enquiry.

Tel: 0707 499 3527

email: sexdis@outsiders.org.uk

Web: www.outsiders.org.uk

telephone 0800 032 3839



Relate

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through the website.

Tel: 0300 100 1234

Web: www.relate.org.uk

Gay, bisexual and transgender people

There are a number of Switchboard charities around the UK offering advice and a helpline for gay, bisexual and transgender people. The London Lesbian & Gay Switchboard acts as a national hub for these services.

Helpline: 0207 837 7324

Web: www.turningnetwork.org.uk

MS Trust publications you may find helpful Books

- MS and me - a self-management guide to living with MS
- Living with fatigue

Factsheets

- Bladder problems
- Bowel problems
- Cognition
- Depression
- Pain
- Spasticity and spasms

Website

- StayingSmart
a website for people affected by cognition problems
www.stayingsmart.org.uk

All these publications are free and can be ordered from the MS Trust. See the contact details inside the front cover.



About the author

Simon Webster,
Information Officer, MS Trust

The MS Trust is a UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

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- Jo Johnson
- Nollie Biggins

Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of this publication.

This publication will be reviewed in three years.

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Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T 01462 476700
E info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353

