Sex, intimacy and MS:

A guide for MEN

Updated October 2024

MS Trust Information Services

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1. Introduction

This book was last published in 2018. Since then, society has become increasingly aware that gender identity exists on a spectrum rather than being binary (male/female). So, in this edition, we have updated some of the language and themes to reflect this and expect it to continue to evolve. As well as cisgender men (males who identify as men), this book may also be relevant to individuals who identify as non-binary who were assigned male at birth, and some trans(gender) women and trans(gender) men – depending on whether they have chosen to have gender-affirming surgery.

Whilst we continue to predominantly refer to men in the text, many of the themes in this book refer to intimacy within partnerships that do not depend solely on identifying with that gender identity. If you feel this book could be useful to you, please read it.

This book has been produced to help people with MS to have an enjoyable sex life.

Everyone's sex life is unique, and so this book is for you whatever your sexual orientation, sexual identity, sexual preferences, or relationship status – be that single, or in a new or long-standing relationship. Equally, MS is a very individual and variable condition, with no two people experiencing the same symptoms in the same way. It's important to remember that not everyone with MS finds their sex life is affected and that not all concerns about sex may be due to MS. It may be that not all of the information in this book will be relevant to you personally – read the sections which are meaningful for you.

This book will discuss some of the complicated factors that contribute to sexual issues for men with MS and some approaches that may help manage these. Scattered through the book are quotes from individuals who share their experiences of living with MS and their tips for minimising its impact on sex and intimacy.

Difficulty with erections, orgasms and having satisfying sex are not unusual. Studies estimate that more than half 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, whatever your sexual orientation and whether you're single or in a relationship.

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 partners or on your own, can have a profound effect on health and wellbeing. 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. These feelings can affect more than just your sex life.

Many people find it awkward or embarrassing to talk about sex. You may think any sexual symptoms must be an inevitable consequence of MS that has to be endured. Some difficulties may be unrelated to MS. You may feel guilt or shame about what you're experiencing. 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 does it include tips for practising safer sex – to protect against the risk of sexually transmitted infections (STIs) or unplanned pregnancies. If you need more information on safer sex, there's lots of sound advice from the FPA (fpa.org.uk) and the British Association for Sexual Health and HIV (bashh.org).

However, by raising awareness of the treatments and advice that are available, alongside ways of managing difficulties that may occur, we hope it will show that you do not need to struggle in silence.

2. Sexual response – how it should work

The terms 'sexual functioning' or 'sexual response' refer to the physical act of engaging in any form of intimate contact or sexual activity. This includes 'non-touch' activities such as sexting, cybersex or watching porn.

Phases of the sexual response cycle

- sexual desire
- arousal
- orgasm and ejaculation
- afterwards/resolution.

Sexual desire

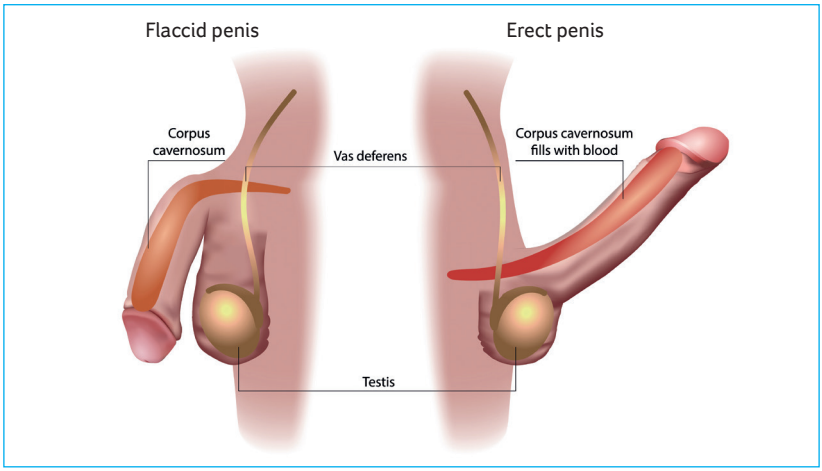
Sexual desire or sex drive (libido) is the urge to take part in sexual activity. Although not fully understood, desire is thought to involve thoughts – including how you think of yourself, how you think about partners, previous positive and negative experiences of sex, cultural and religious factors, and your mood – together with physical factors such as hormones, chemical processes 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 signals within the autonomic nervous system – the section of the nervous system outside conscious control – which respond to physical stimulation such as touch.

Erections that last long enough for sexual activity also involve messages from the brain's response to erotic stimulation from sight and thought, such as sexual images, memories or imagining sexual situations and, well, depending on your own preferences, pretty much anything.

Erections can happen during the night or when waking up. These erections are an automatic response by the body and are not associated with erotic arousal. The presence or absence of these 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. It causes muscular contractions in the lower pelvic muscles around the genitals and anus, accompanied by increased heart rate, blood pressure, and breathing. 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 to have an orgasm without ejaculating (dry orgasm) or to ejaculate without reaching orgasm. If one happens without the other it 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.

3. 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. 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 that might help them. Because of popular culture, Viagra is seen, wrongly perhaps, in a positive light as a drug that enhances sexual performance rather than with the more negative connotations of being a treatment for a medical symptom.

The downside of this is that it can encourage the idea of male sexuality being solely about penetrative sex and performance. It assumes that sexual problems are all about difficulty with erections, and tends to suggest that sexual difficulties can be easily and solely treated with a pill.

For many people with MS, sexual issues stem from a combination of physical, psychological, emotional and social factors. These fall into four 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 depression or worries about work or finances or lowered self-esteem
- from issues within the relationship, that may be related or unrelated to a diagnosis of MS.

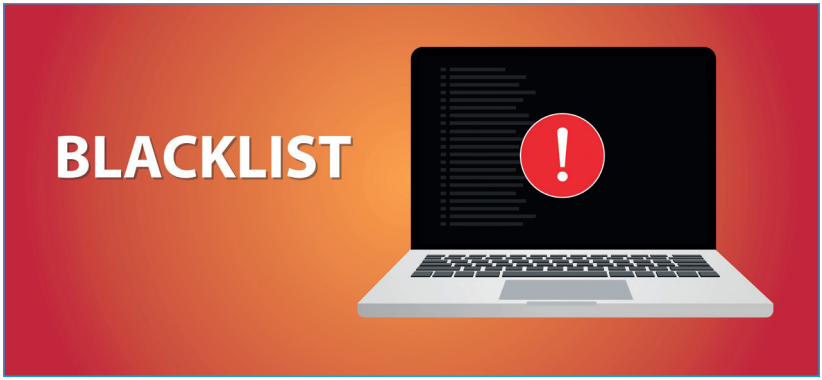
Effective treatment needs careful analysis of all the factors that are affecting you and then finding the right approach to help address these. For example, if fatigue affects your sexual performance, a pill that makes it easier to achieve an erection is not going to address the problem of physical stamina.

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

Restoring the ability to maintain an erection might mean that more suitable alternatives are overlooked or ignored. Rather than focusing solely on the pursuit of erection and orgasm, more mutually caring and supportive approaches, for instance focusing on touch and sensuality, might be more fulfilling and rewarding.

Self-medication

You may be tempted to turn to the internet for help with your symptoms. This offers a degree of anonymity and also a wide array of potions, creams and devices that often make bold and unsupported promises. These options need to be approached with a great deal of caution. There are plenty of unscrupulous sites trading as online pharmacies and selling drugs of dubious quality and efficacy.



With all medication, there is a risk of interactions with other treatments, whether for MS symptoms or other conditions. When remedies 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 always to do with your 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 several 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 or hypogonadism.
- Psychological causes, such as anxiety, stress, relationship difficulties 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 factors. Your GP may be able to test for some issues, such as diabetes, or checking whether your testosterone is within normal limits.

4. Reduced sexual desire

Living with MS can have a profound impact on your 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 influence 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 can 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 factors can also affect sexual desire. It is not always easy to tell if it's because you are having difficulty in getting an erection or in reaching a satisfactory orgasm that is causing you to have a reduced interest in sex, or if it is waning interest in sex that is making it hard for you to get an erection or reach orgasm.

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.

Loss 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 satisfying 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) or counselling can help challenge negative thoughts, feelings and behaviours and help to find new, positive ways of managing.

Mindfulness is a meditative technique that involves learning to focus attention on emotions, sensations and thoughts in an accepting and non-judgemental way. By focusing fully on the present moment rather than on regret for the past or worries about the future, mindfulness helps to break the cycle of negative thoughts and emotions.

Acceptance and commitment therapy (ACT) helps people to acknowledge negative thoughts and feelings as normal and to find ways to manage them. For instance, you might notice that your negative thoughts are due to your mind acting like a bully in your head, telling you that you are no longer attractive, partners will not be interested and sex will fail. With practice, you can learn to recognise and manage these thoughts and have a successful sex life despite them.

If you feel yourself to be sexually unattractive, it may have 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, 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 partner(s), 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 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. It has a role in reducing stress, low mood and can help improve fatigue. This does not have to 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(s).

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

Focusing on sex can sometimes get in the way of the romance that brings people together and distract people from the companionship that is an essential part of a relationship. 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.

Taking the attention away from sex itself is an approach sometimes used by sex therapists. This distance can help you reassess what is important to your relationship. You can also consider your 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 partner 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."

5. Getting to know your body

We are all different and people have a natural tendency to unconsciously assume that we feel physical sensations in the same way, and the addition of symptoms such as pain and altered sensations can make this even more complicated.

For example, you may prefer that your partner(s) use much greater pressure when they touch an area than they expect and they might want a much lighter touch than you would find pleasant. You may have parts of your bodies that you don't enjoy being touched at all.

Body mapping (or sensate focusing) is a simple technique that you can use alone or together to increase intimacy and rediscover sexual pleasure. It involves exploring your body with touch to find out exactly where touch gives you pleasure or where it feels uncomfortable.

It can be helpful to draw a map of each other's bodies. By giving up assumptions about what does and doesn't feel good you can test what works and what doesn't. Remember that you can do this on your own, too.

If you decide to give body mapping a try, it is best to find somewhere that you feel comfortable and won't be disturbed for at least 15-20 minutes, while you take your clothes off and lie down.

Body mapping exercises

Taking a scientific approach to pleasure can sometimes be helpful

1. Begin with a basic outline of your body, adding on hair as this can affect sensation.
2. Work out how it feels to be touched in a specific place. Explore each part of your body in turn and take notes on how each area feels.
3. Colour code each area with whether it feels good or bad. You can use the colours we have suggested on the diagram on the next page or choose your own.

For each area note down

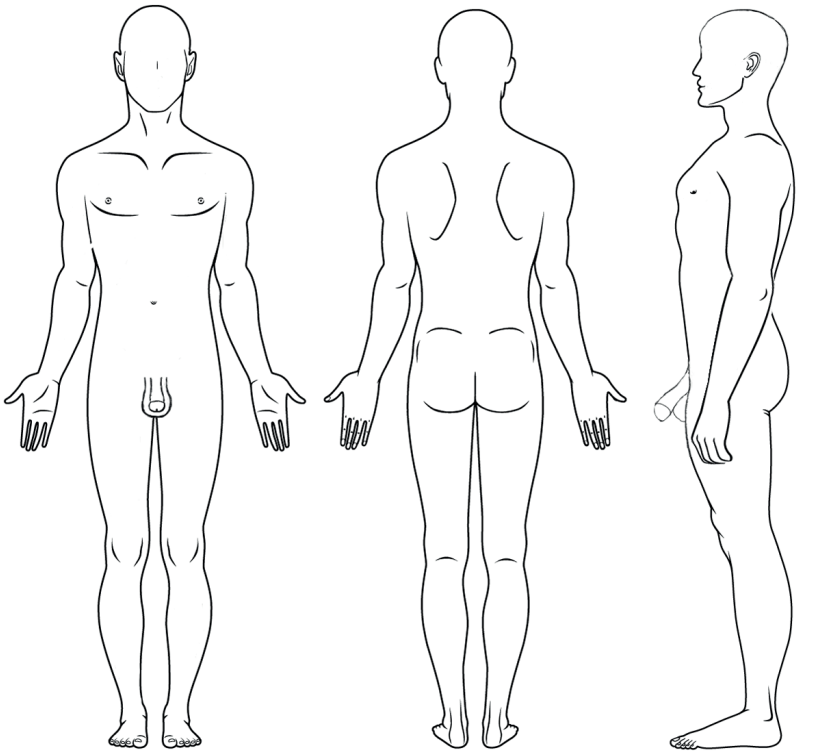
4. How much pressure? What level of pressure feels good or bad, eg light brush against body hair, light touch, medium touch, deep pressure.
5. What motion? What direction feels best, eg up and down, side to side, round and round etc.
6. What speed and rhythm? Do you prefer fast motions or slow motions or changing rhythms?
7. What do you like to be touched with? You can try touching with different things and with or without lubrication, eg hands, body parts, hair, feathers, silk, leather, vibrating toys.
8. What temperature do you enjoy? Hot, warm, cold?

Remember the aim of the exercise isn't to climax; in fact, it's usually recommended that you don't attempt this initially as it can defeat the purpose of the exercise. You may also want to make different maps for different circumstances as touch preferences can change based on where you are in the sexual response cycle. You may enjoy different forms of touch as you move from unaroused > to excited > to plateau > to orgasm > to resolution.

Your maps may also differ based on your emotional state, medication you have taken, changes to symptoms and age.

As your experience with likes and dislikes grows, having a map to refer to will become less important. But starting out with one can help you understand what works and what doesn't.

Consider photocopying this image so you can use it more than once.



Colour Key

- Feels very bad or irritating
- Feels a little bad or irritating
- Feels neutral
- Feels good or arousing
- Feels very good or arousing

6. 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 several 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 initiate sex.

Some men with MS can get erections from psychological stimuli but struggle to get erections by direct stimulation. Consider concentrating on visual or auditory stimulation if this works for you.

Other MS symptoms

Several MS symptoms can make it difficult to get or maintain an erection. If you have pain or numbness in the genital area, otherwise pleasurable sensations may become uncomfortable.

Depression or reduced attention span or concentration may distract you.

Fear of symptoms can also play a role. For example, worry that sexual activity will cause spasms or fatigue, or that you might wet or soil yourself.

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

Erectile dysfunction should be properly assessed as there may be other factors causing or contributing to it. Your assessment should include a physical examination and some blood tests for conditions such as diabetes and hypogonadism. Your doctor may suggest diet or lifestyle modifications before prescribing medication.

There are drugs available that can improve the ability to achieve an erection. However, effective management of the symptom requires an assessment of the whole person, not merely the penis. Medication should be seen as part of the treatment of symptoms, not as a complete solution.

Medication

Erectile dysfunction can be treated with a class of drugs known as PDE5 inhibitors. PDE5 (phosphodiesterase type 5) is an enzyme that controls blood flow in the penis. Altering levels of PDE5 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.

There are four PDE5 inhibitor drugs:

- sildenafil citrate (Viagra is the best-known brand name, though non-brand name (generic) versions are now available)
- tadalafil (Cialis)
- vardenafil (Levitra)
- avanafil (Spedra).

Generic sildenafil can be prescribed without restriction by a GP to anyone with erectile dysfunction. A version called Viagra Connect can also be bought from high street pharmacies without a prescription, though you will need to talk to a pharmacist to make sure this is an appropriate drug for your symptoms.

The other drugs are controlled by NHS guidelines that limit the conditions for which erectile dysfunction drugs can be prescribed. MS is one of the permitted conditions. You do not have to be in a relationship to be given a prescription.

How you use your medication most effectively needs careful thought. Whilst the drugs can provide the ability to have penetrative sex, they don't of themselves create the anticipation and pleasure of sex. If taken without planning, the opportunity to have sex may occur when your partner isn't in the mood, making intercourse seem functional, imposed or unsatisfying.

The first time you try one of these medications during sexual intimacy, you may wish to see how effective it is without the pressure of penetration. This may help increase relaxation and reduce performance-related anxiety for the next time.

Each of these drugs has similar side effects, which include headaches, flushing, upset stomach, visual disorders, nasal congestion and dizziness. None should be taken if you are receiving treatment with drugs containing nitrates, such as those used to treat angina. They must be used with caution if you have an existing heart condition, problems with liver or kidney function or low blood pressure. It is also recommended to avoid taking these drugs with alcohol.

You can find out more about PDE5 inhibitors for erectile dysfunction in a useful leaflet from the British Association of Urological Surgeons, which you can find in the Resources section at the end of this book.

"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 double vision and problems with my eyesight for several months as a result. Don't do it, kids!!"

Sildenafil citrate (Viagra)

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 altitude sickness.

Sildenafil 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.

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

Tadalafil (Cialis)

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

Tadalafil 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 sildenafil and vardenafil, the effects of tadalafil are not delayed if taken with food.

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

Vardenafil (Levitra)

Vardenafil 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 sildenafil, it will take longer for vardenafil 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 vardenafil in men with MS.

Avanafil (Spedra)

Avanafil is the most recent of the PDE5 inhibitor drugs to become available. It is absorbed more quickly than the other drugs and can be taken 15-30 minutes before sexual activity. It may take longer to work if taken with food.

Although found to be effective in more general studies, there has been no published research into the effects of avanafil in men with MS.

Other treatments

If the first-line drugs (ie those that tend to be recommended first as a treatment, usually due to factors such as effectiveness, safety and cost) are not effective, there are other approaches that can be tried.

Alprostadil (Caverject, Viridal Duo, MUSE, Vitaros)

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) or inserted with an applicator into the tip of the penis (under the name MUSE or Vitaros).

Unlike the previously mentioned drugs, alprostadil will cause an erection without sexual arousal. This happens almost immediately with Caverject or after a few minutes with Viridal Duo. With MUSE it is necessary to massage the penis for a few seconds to help distribute the drug and an erection will occur in five to ten minutes. This process can involve a partner and be part of foreplay. Whilst waiting for the drug to have its effect, 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.

An erection due to alprostadil will last for about 30 minutes to an hour.

Side effects of Caverject and Viridal Duo can include pain in the penis or groin and bleeding around the injection site. Less frequently, the erection may not subside for several hours, known as priapism. Priapism is a prolonged erection (over four hours) which is maintained without sexual stimulation and persists despite ejaculation and orgasm. It is a medical emergency and needs urgent medical attention by a urologist as it can cause tissue damage.

A side effect with MUSE and Vitaros 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. MUSE and Vitaros 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.

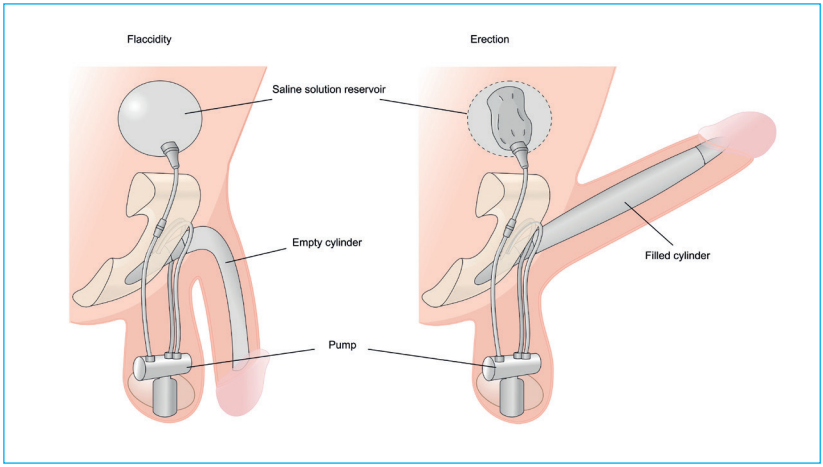
The band can safely stay in place for up to 30 minutes.

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 those who are not in a stable relationship. But for some it can be sexy and incorporated into foreplay. There are no rules.

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. Insertion of prostheses carries risks of infection and so they are rarely prescribed to MS patients.



7. Delayed or absent orgasms and ejaculation

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

When your sexual performance is affected by MS, you are more likely to experience difficulty or inability in reaching climax, even if your 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 several possible causes for this. MS can cause nerve messages in the spinal cord to be interrupted or blocked. Pain, numbness, fatigue or reduced concentration 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 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 or tiring to maintain.

Delayed ejaculation can also be due to psychological issues. Both concerns about MS and its effect on self-image, and worries unrelated to MS can be to blame.

Anxiety about performance and the focus on orgasm can have a negative effect – particularly if you have had difficulty reaching climax before. For some, these anxieties can be reduced by trying to see sex

less as a functional process based on penetration and orgasm and more as a pleasurable, sensual experience.

"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."

Retrograde ejaculation occurs when the bladder neck muscle is not functioning. Therefore the ejaculate goes into the bladder rather than being expelled through the penis. Causes of this include prostate medication, prostate surgery and neurological conditions including MS. This requires no treatment, just for patients to be aware, and is only important for those men trying to achieve conception.

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 feeling 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."

Fantasise

Use of fantasy may make it easier for you to orgasm. You may prefer to keep these fantasies to yourself, or you may want to share them. The mind is one of the most important sexual organs, so make the most of it.

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 are in a relationship, finding toys that everyone enjoys is important and can add a new aspect to your lovemaking.

Vibro egg

Double vibro egg

Vibrating penis ring

"My partner 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 just don't like the idea. 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.

Metal love balls

Prostate stimulator

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.

8. The effect of other MS symptoms

The effects of, or worries about, other MS symptoms can affect sex. It is important that the impact your symptoms have on 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 and on our website (see Section 11 for details). This section looks at 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 aspects 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."

Talking to partners 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 times 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

ideas such as masturbation or oral sex may be more rewarding.

Weakness

Weakness is often linked with fatigue. If muscles are weak, movement requires increased effort which leads to additional fatigue. Weakness may make some sexual positions difficult to maintain or achieve. If so, talk to a physiotherapist who may be able to offer suggestions on sexual positions that take account of weakness. You could experiment with your partner(s) playing a more active or dominant role, which may reduce the impact of weakness and could 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 your being tense and over cautious, or even avoiding sex altogether. Anti-spasticity medication can help, although some of these drugs may 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 your arms or legs that are comfortable but still allow a range of movement. For example, if lying flat on your back causes difficulties, use a pillow or a rolled-up towel under your knees, bottom or the small of the back to break up spasticity and reduce the risk of spasms.

It can be helpful to 'practice' positions when you are not being sexual to see what works without the pressure of performing.

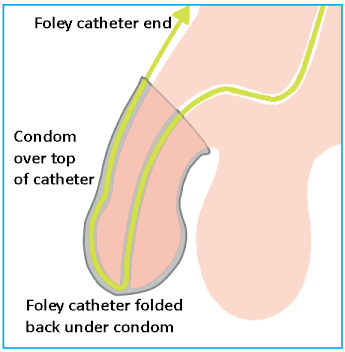
"Finding just the right position during sex can be tricky, and sometimes comical, as I try to avoid those positions where my leg starts banging away rhythmically, or my calf muscles or thigh muscles go into agonising and passion-killing cramps."

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 concern. Going to the toilet before sex can help with this. If you need to use a catheter, 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.



If you use an indwelling catheter, this doesn't necessarily prevent sexual activity. It can be folded along the shaft of the penis and held in place with tape or a condom during intercourse.

A suprapubic catheter 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.

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

If you are worried about soiling yourself, this 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. There are also anal irrigation systems such as Peristeen and Qufora which are good for ensuring the rectum is empty, which may give you the confidence that you are not going to be faecally incontinent.

Micro enema

Anal plug

Peristeen

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.

"Simply changing positions during sex to avoid areas which are sensitive coming into contact with sheets or skin can help."

The body mapping technique outlined in Section 5 can be a good way of discovering where you do like to be touched. But, if being touched causes you pain, body mapping may be too uncomfortable for you – you might have to experiment a bit to see if it can be of any benefit.
If you find that hypersensitivity means that touch or sex aren't an option, the following could provide you with some sexual pleasure and can be done on your own or with your partner(s):

- talking sexy or sexting
- watching erotic films
- reading erotic novels.

There are medications that might help with hypersensitivity, so do talk to your specialist if it is an issue.

"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 it is 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.

9. 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(s), a friend or a health professional such as your GP or MS nurse. It may be anonymously via a helpline or online group.

Talking to partners

If you are in a relationship, making sure partners understand they are not the source of sexual difficulties can be a great relief to everyone. Without this, they might interpret changes in your desire or arousal as a reflection on themselves – a sign of your waning affection or 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."

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 avoiding mentioning difficulties with sex may work in the short term, over time these issues will become apparent and may lead to disappointment and conflict.

Talking to professionals

Broaching the subject of sex with health professionals can be really difficult for some people. However, 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 often has an impact upon sexual activity, so don't be shy! If they don't understand, 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 to 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 – either 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 is 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 (see Resources section).

10. 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 these feelings might be, they are entirely normal. People are not alone in feeling this way.

So, if you are a man with MS, remember to consider your partner's perspective even as you deal with your own challenges. And, if you are a partner of a man with MS and reading this book for insights, know that it is okay to think about your own needs as well as your partner's when it comes to sex and intimacy. In fact, it's very important!

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 partners view 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 has taken up belly dancing, 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 one person'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 partners have their own sexual needs.

Don't forget that partners need attention and wooing too. Just because you're up for it doesn't mean they are too.

"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 strengthen their relationship. Talking about the physical issues and being open about the emotional responses of everyone can help lessen resentments that build up and create a shared challenge faced together rather than repressed, resented private battles. Rather than being stuck behind the wall of what can't be done, men with MS and 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 them choose and 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."

“MS 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.”

11. Resources and links

Organisations

College of Sexual and Relationship Therapists (COSRT)
An organisation for therapists specialising in sexual and relationship issues. The website includes a directory of psychosexual therapists.
Tel: 0208 106 9635
Email: info@cosrt.org.uk
cosrt.org.uk

Institute of Psychosexual Medicine
A charity which provides training and undertakes research in psychosexual medicine. The website includes a directory of doctors who specialise in sexual problems.
Tel: 020 7580 0631
Email: admin@ipm.org.uk
ipm.org.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.
Tel: 07900 957 393 (weekdays 11am to 5pm)
Email: sexdis@outsiders.org.uk
outsiders.org.uk/outsidersclub/helpline/

Relate
Offers advice, relationship counselling, sex therapy and support face-to-face, by phone and through the website.
Tel: 0300 100 1234
Email: Relate.Enquiries@relate.org.uk
relate.org.uk/relationship-help/talk-someone

Switchboard
Offers information and support for gay, bisexual and trans people.
Helpline: 0800 0119 100 (every day 10am to 10pm)
Email: hello@switchboard.lgbt
switchboard.lgbt

MS Trust
The MS Trust website has more on sex and relationships as well as a range of information on all aspects of living with MS.
mstrust.org.uk/sex

If you have a question about MS, our enquiry service can help you find the information you need.
Tel: 0800 032 3839 (Monday to Friday 10am to 4pm)
Email: ask@mstrust.org.uk

Other publications

Dare: What happens when fantasies come true
Twenty couples explore fantasy. How some of them manage to safely enact their fantasies by Tracey Cox.

The Ultimate Guide to Sex and Disability
A self-help sex guide for people living with disabilities, chronic pain and illness by Miriam Kaufman.

Desires Reborn
Erotic stories involving people with disabilities by Penny Pepper.

The Body Image Workbook
An eight-step program for learning to like your looks by Thomas Cash.

Tactile Mind
Nude photographs for the blind by Lisa Murphy.
tactilemindbook.com

The New Joy of Sex
Written by Susan Quilliam, a disability-informed author.

The Sex Book
Explores the subject of sex, health and sexuality in a straightforward and adventurous way by Suzi Godson, Mel Agace, Robert Winston Cassell.

Enabling romance
A guide to love, sex and relationships for people with disabilities (and the people who care about them) by Ken Kroll and Erica Levy Klein.

How I Became a Human Being
A disabled man's quest for independence by Mark O'Brien with Gillian Kendall.

Sex for one: the joy of self-loving
Discusses masturbation as an expression of self-love, how to fully enjoy the pleasures of masturbation and how it can enhance sex with a partner by Betty Dodson.

Phosphodiesterase type-5 (PDE-5) inhibitors for erectile dysfunction
Information from the British Association of Urological Surgeons (BAUS) about tablets to treat impotence
baus.org.uk/_userfiles/pages/files/patients/leaflets/Viagra.pdf

Sex aids

Ann Summers
Website, mail-order catalogue and chain of stores throughout the UK.
Tel: 0333 440 6969
annsummers.com

Love Honey
Website and mail-order catalogue.
Tel: 0333 103 6969
lovehoney.co.uk

Spokz
Website includes a specialist range of sex aids to better enable sex – including masturbation aids, lubricants and massage oils, and furniture and cushions that can help improve sexual mobility.
Tel: 01543 399760
spokz.co.uk

Notes

Notes

About the authors

Information Team, MS Trust

The MS Trust is a UK charity for people with MS, their family and friends. We have a personalised enquiry service and provide extensive information through our website, social media and printed publications.

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Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. **ask@mstrust.org.uk**
W. **mstrust.org.uk**

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