

# MS Essentials

For people living with MS

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## Sex, intimacy & relationships

Sexuality – how we think and feel and express ourselves sexually – is an important part of life. But having MS can sometimes affect this. Maybe how you feel about yourself sexually or your desire for sex has changed. Or maybe MS has affected your ability to have sex and to feel sexual pleasure. Perhaps you are worried about starting a new relationship and how a potential partner might react to your MS.

If any of these issues are affecting you, then you're not alone. But having MS does not automatically mean that your sexual and emotional life has to stop being fulfilling and fun. Whatever your relationship status or sexual orientation, this booklet offers tips for overcoming some of the difficulties you might experience as a result of your MS.

Sexuality is as individual and personal as MS, so we don't try to cover everything here. This booklet aims to help you explore what works best for you (and your partner if you have one) so that you can continue to have fulfilling sexual and intimate relationships – whatever that means for you.

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### This booklet

Throughout this booklet we refer to other organisations that can help with particular issues – just look for the **i**. You'll find their details in 'Useful organisations' at the back of this booklet.

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# What are sexuality and intimacy?

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

Sexuality and intimacy are very private and personal. They can mean different things for different people – more than simply whether they are straight or gay. For some people, they mean sharing all aspects of their life with one partner in a committed relationship. Others explore their sexuality with a range of different partners or alone. For anyone, sexuality and intimacy can involve sex, love, fun, closeness, trust, honesty, openness and communication – as well as vulnerability, fear of rejection and sexual difficulties.

Sexuality and intimacy are also about more than just intercourse and orgasm. Caressing, kissing and mutual masturbation are all ways to be intimate and experience sexual pleasure – in fact, there are as many ways to be intimate as there are people.

You might find MS has physical and emotional effects on sexuality. The rest of this booklet looks at these effects, and at how you might adapt to them, and perhaps find new ways to be intimate.

## Myths

One of the myths about sexuality, often reinforced by the media, is that there is some kind of sexual norm – that people have to look a certain way, or behave in a certain way, to be sexually attractive. In reality, everyone is different and has different ideas as to what they consider attractive. Whatever a person's gender, age, size, sexual identity or physical abilities, they are still – or have the potential to be – a full sexual being.

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# How might having MS affect sex and intimacy?

“ I felt I couldn't talk to him about my problems. What have I got to complain about when he's got MS? It took us a long time to recognise that this was causing a big gap between us. We try to talk to each other about everything now. – *Lesley* ”

## Partners and relationships

People with MS and their partners often report that living with the condition creates both physical and emotional barriers – and that their relationships suffer as a consequence.

For some couples, worries about MS and uncertainty about the future can cause a breakdown in communication and intimacy. There might be times when one or both of you feel confused or rejected, angry or isolated. There could be a rebalance in the relationship. Perhaps the person who did most of the supporting now needs to be supported. Or perhaps your partner is also your carer, and this is causing a strain in your relationship. Sometimes you might need encouragement and support just when your partner is least able to give it.

Later in this booklet, in the 'Things you can do' section on page 15, we look at ways to deal with the impact of MS on relationships. You might also want to read the MS Society booklet *Living with the effects of MS*.

## Changes in desire (libido)

If you feel like you're no longer interested in sex, you're not alone. Lack of desire can be a direct result of the MS. But it can also be the result of living with the condition. For example, adjusting to a diagnosis, or to new symptoms, can lead to a period of sadness or grief, which can affect sexual desire.

How you feel about your MS can also affect your libido. Some people feel embarrassed about having MS, or feel uncomfortable because of particular symptoms. Self-esteem can also have an impact – if you feel less attractive because of your MS, or because of changes it has made in your life, then this can affect your desire for sex.

Of course, it's not just having MS that can affect things. Stress, having children, the menopause – these could all have an influence. Sexual desire and activity change throughout most people's lives, and change with age. Emotional relationships can also affect sex drive. Anger or resentment in particular – whatever it's related to – can affect the desire for sexual activity in both partners.

Sex drive doesn't always match up all the time in a partnership. If you don't feel 'sexy', it can be difficult to be the one to initiate sexual activity. And if your partner wants sex and you don't, this might be awkward too.

While there are no instant remedies that can help to increase libido, there are things that can help. Sometimes you might find the desire comes after you start to engage in sexual activities, such as kissing. In many cases, anyone who feels like they're not interested in sex any more can get turned on – but it might take a bit longer. Talking to your partner about it can help, as can some of the techniques listed on page 15.

## **MS-related sexual difficulties**

MS can directly cause sexual difficulties. Sexual arousal, response and orgasm require messages to be sent between the brain and sexual organs, via the spinal cord. If there is MS-related nerve damage in the parts of the brain and spinal cord that are involved, this can have an effect on sexual function. The effects this damage can have on men and women – and ways to help manage them – are outlined in the next two sections.

### **Getting it in perspective**

Not all sexual difficulties are caused by MS. Although studies suggest between 50 to 80 per cent of women with MS are affected by some form of sexual difficulty, this compares to approximately 40 per cent of all women in the UK. Similarly, while the number of men with MS experiencing sexual difficulties is higher than in the general population, around 22 per cent of all men are also affected. Other factors can be involved, such as having children and getting older. It has been estimated that over half of all men aged over 40 experience some form of erectile problem, and this figure increases with age.

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## Sexual issues for women

“ You’re told that you will grieve for the loss of your health, but you grieve for your sexuality too. I used to have multiple orgasms and now I don’t have any. That’s a loss. But I can still have sex and I still have feeling, so I tell myself it could be a lot worse. – *Gail* ”

### Vaginal dryness

Vaginal dryness can make sex painful or uncomfortable for a woman. It can be a result of MS, or it could be a side effect of certain medications such as anti-depressants. Menopause can also cause dryness. Using lubricant can help to overcome it – some women find water-based lubricants help, like the Durex range, Sensilube or Astroglide. These lubricants are widely available at chemists and in some supermarkets as well as in sex shops or online. Don’t be afraid to use lubricant liberally. If you’re using condoms, make sure it is water-based.

Some women prefer silicone lubricants, such as some of the Durex range or EROS, as they stay slipperier longer. They can also increase sensitivity which can be pleasurable for some women. However, they may be harder to wash off your body, clothes, or sheets since they are water-resistant. They can also cause allergies in some people. They also shouldn’t be used with condoms.

If you think your medications might be causing your vaginal dryness, you can speak to your doctor about it. If you feel uncomfortable talking to your doctor about sexual issues, there are some tips on page 14.

### Orgasms

One of the main sexual issues for women with MS is being less able to orgasm. While there is currently no medication to fix this problem, there are things you can do that may help. Many women find that they can still have orgasms, but it takes them longer, and can require more stimulation.

Many women find that foreplay is the most pleasurable part of sexual activity, so spending more time on this can help you to reach orgasm. Fondling, massage and mutual masturbation are all things you could explore. Another way of increasing the possibility of orgasm is guided imagery or exploring sexual fantasies, as this can increase arousal and libido.

Lots of women use vibrators, either alone or with a partner. They are one of the easiest ways to have an orgasm. This is because they can produce subtle but intense stimulation of the clitoris and surrounding area – which is how most women achieve orgasm. It can also help increase lubrication. Women often say the most effective vibrators are those that include an external vibratory feature. You can use it in the same way that you would use your hands or in any way that feels pleasurable to you – or your partner could use it with you. If you have problems with spasticity, bear in mind that having too high a setting on a vibrator can make it worse.

Vibrators are easily bought these days from a range of shops, including high street shops such as Ann Summers. If you're a bit self-conscious about buying one, you can also get them online. If you have problems with dexterity, there are some you can buy that fit onto your hand like a glove, or that have large handles. Some women prefer mains operated vibrators as they can produce a much more intense sensation. Equipment that is meant for massage can also be useful as an external vibrator.

### **Contraception and MS**

Certain medications for MS symptoms, such carbamazepine (used to treat spasms), can make the contraceptive pill less effective. The same applies for certain complementary therapies, such as St John's Wort (Hypericum extract) that some people take for depression. Speak to your doctor if you're concerned about any possible interactions. For more information on contraception, contact the FPA. 

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## Sexual issues for men

“ It’s more difficult physically, but not impossible. We’ve had to learn to adapt, just as with everything else. – *Brian* ”

### Difficulties getting and maintaining an erection

Erectile difficulties are common, for men both with and without MS. About 70 per cent of men with MS experience difficulties. These generally start some years after the first symptoms of MS.

For a man to get an erection in response to erotic situations or thoughts, the nerve pathways between the brain and the base of the spinal cord need to be intact. On the other hand, erections in response to genital stimulation use nerves in the lower part of the spinal cord, and messages do not need to be sent from the brain to the sexual organs via the spinal cord. So depending on where the nerve damage is, a man with MS may find that he is able to get an erection in response to genital stimulation, but not in response to erotic situations, or vice versa.

As well as MS-related nerve damage, there are various other potential causes of erectile dysfunction. These could be the side effects of medication, psychological factors or an unrelated health condition, for example. By talking to your doctor or MS nurse about it, you can find out what’s causing it and get these other causes treated.

If you find it difficult to approach the topic with your doctor, there are some tips in ‘Talking to health care professionals about sexual issues’ on page 14 that you may find helpful.

The Sexual Advice Association has more information about erectile difficulties, possible causes, and ways to deal with them. [i](#)

### Medication

“ We got by before, but the little blue pills just gave me my sexuality back, which was very welcome. – *Cliff* ”

Men with MS who are experiencing erectile difficulties can be prescribed treatments for it on the NHS. The three main oral medications are Viagra (drug name sildenafil citrate), Levitra (vardenafil) and Cialis (tadalafil). They work by enhancing blood flow into the penis, and increasing any erectile response that can naturally occur – either through genital stimulation, or erotic thoughts and situations. It’s important to be aware that they don’t cause spontaneous erections: sexual stimulation and foreplay are still necessary.

One study looking at Viagra for men with MS and erectile problems found that 95 per cent of the men taking part showed both improved erections and levels of sexual activity after taking the drug. Research has shown Cialis and Levitra to help in 80 per cent of men experiencing erectile problems, although they haven't been tested specifically in men with MS.

You should discuss with your doctor which drug might be suitable for you. All three drugs work in a similar way, but vary in how quickly they take effect and how long they remain active. It might take a while to find the right dosage for you. Your doctor might only prescribe you four or five tablets per month. If so, you can ask for more.

The NHS Choices website has more information about the three different drugs, including when they should be taken and any possible side effects. [i](#)

Even though there are all sorts of drugs for sale on the internet, this group of drugs do need to be prescribed by your doctor. They may not be suitable for everyone, so it's important that they are prescribed by someone who knows your medical history and other medicines you take (and any possible interactions). They can discuss any potential side effects with you.

## **Other treatments**

Not all men find pills effective in treating erectile difficulties. There are other treatments available.

One option is prostaglandins, a man-made hormone that helps to stimulate blood flow to the penis. There are two different ways to use prostaglandins – self-injecting into the base of the penis, or inserting a small pellet into the urethra (this is the tube in the penis which urine passes along). There are currently two branded drugs for the first method – Caverject and Viridal Duo – and one for the second – MUSE.

Another option is a vacuum pump, which uses vacuum pressure to create an erection and a rubber ring to maintain the erection. While this can help with erection, it will not bring back sensation. Your penis will also feel very cold, which is another issue to consider.

There's more information about these different treatments on the NHS Choices website. [i](#)

## **Ejaculation and orgasm**

Ejaculation and orgasm are much more complicated processes than genital arousal, and are almost impossible to achieve without intact connections between the spinal cord and brain. It has been estimated that between 35 and 50 per cent of men with MS experience problems with ejaculation. Problems can include delayed ejaculation or not being able to ejaculate at all.

There is no treatment yet that really helps with ejaculation. Being able to maintain an erection for longer can help, but ejaculation may remain a problem. Although MS does not affect fertility itself, men who are unable to ejaculate might have a problem if trying to father a child. If this is the case, you can ask to be referred to a fertility clinic for help.

It's worth remembering that ejaculation and orgasm are not the same thing. Orgasm is possible without ejaculation, and sexual activities with no orgasm or ejaculation are still sex. Spending more time on foreplay can also help you to become aroused, which can help. Stimulation to the penis, perineum or anus with a vibrator can be helpful.

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## MS symptoms that have an indirect effect

In this section, we look at ways to manage MS symptoms that might have an indirect impact on sex and intimacy.

There's more information about how to manage the non-sexual effects of these symptoms in the MS Society's series of information booklets. For copies, call 020 8438 0999, email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk) or visit the MS Society website.

## **Spasticity**

Cramps or spasms in the legs might make sexual intercourse physically difficult. And spasms can sometimes be painful during or after sexual activity.

So if you take any medication for spasticity, it might help to take it just before sexual activity – although how much it will help will depend on how quickly they take effect and their impact on sexual function. It's a good idea to discuss changes in your medication patterns with a doctor first.

Exploring new options with your partner can also make a difference. You might find that some positions are more comfortable than others. For some people, massage helps relax their muscles – and it can also help create intimacy and closeness.

### **Muscle weakness**

Muscle weakness might mean that sex in certain positions is difficult. Changing positions might not always be easy. Some people are happy to be supported by their partner, or have their partner move them about, but this is not a happy solution for everyone.

Some people try using a rolled up towel as support for their lower back, or using pillows to hold them in one position. Furniture around the house, such as a bed or chair, might also be useful. You can also buy supports, slings and other pieces of ‘sex furniture’ that are designed to help support you in a comfortable position during sexual activity.

*The ultimate guide to sex and disability*, available to borrow from the MS Society library, has more information about what you can buy and where from.

### **Sensory symptoms and pain**

Sensory changes can have a big impact on sexual activity – it can be difficult to get ‘in the mood’ when even the lightest touch causes discomfort, or if you can’t feel any touch at all. And strange or painful sensations don’t have to be in the genital area to make being touched painful, irritating or uncomfortable.

There are medications that can help with these sensations, such as amitriptyline, carbamazepine, gabapentin and phenytoin. Not all pain will be treatable, but many people find ways to work around it. Body mapping (see page 16) can help to identify areas that are less sensitive to touch.

As with other sexual problems in MS, some experimentation and good communication between partners should help too. You could encourage your partner to look at your face during sex, and to be alert to any non-verbal signals that indicate when something is painful to you.

## Bladder and bowel problems

“ Let’s face it, sex can be an undignified business at the best of times. You have to see the funny side of life. If we can laugh at things together, somehow it puts them into perspective. So what if the plumbing goes wrong from time to time? We love each other, that’s the main thing. – *Nick* ”

The nerve pathways that affect bladder, bowel and sexual function are next to each other, or shared. So some people with MS experience bladder and bowel problems during intercourse.

For some people, the thought of having an ‘accident’ during sexual activity – particularly with a new partner – can kill the mood, and may even cause them to shy away from intimate physical contact altogether. Fortunately, there are ways to help manage bladder and bowel problems, and to reduce any impact they might have on sexual activity.

If you have problems with urgency or continence, going to the toilet (or self-catheterising, if you do this) just before having sex can help. If you take any medications for bladder problems, taking them about 30 minutes before sex can minimise bladder contractions during sex.

Finding positions which don’t put pressure on your bladder can also make a difference. Men concerned about small amounts of urine leakage could wear a condom. But if you don’t mind a bit of leakage, lying a towel underneath you on the bed may be enough.

As with other MS symptoms, talking about the issues and how they affect you can help to make bladder and bowel problems easier to deal with during sex. Of course, even with the best communication, not everyone feels comfortable with dealing with these problems. Other forms of physical closeness and sexual contact may feel better than sexual intercourse. Each couple is different, and it may take some trial and error to establish what suits you and your partner best.

The Bladder and Bowel Foundation has more information about managing continence issues and sexual activity. [i](#)

### **Can I have sex if I'm using a catheter?**

Yes, although you may need to take a little extra care. Women can tape their catheter securely to their stomach, emptying the collecting bag before sexual activity, and putting extra tape around the top ring to reduce the chance of leakage. Men can keep an indwelling catheter in place using a condom. There are also different sexual positions you can use to avoid putting pressure on the collecting bag. It is important to ensure any new positions are comfortable for you and your partner and do not cause any anxiety during sexual activity.

### **Cognitive difficulties**

Many people with MS experience some changes in their concentration, thinking or memory. Sometimes people 'drift away' during sex, finding it hard to sustain interest. This can cause misunderstandings.

If you find that you tend to drift off, keep trying to bring your attention back to what you are doing. It's important that you aren't tense or in a hurry, or preoccupied with something else. Maybe you're putting pressure on yourself to feel turned on or to have an orgasm. Try to relax and just enjoy the sensations – worrying about how turned on you are will make it less likely that you will be.

It can help to talk this through with your partner, so they understand that this lack of concentration is a genuine symptom of MS. Together, you might find ways of compensating for it, such as avoiding potential distractions and creating a romantic mood and sensual environment.

### **Mood and emotions**

MS can affect your emotions as well as your body, and people with MS are more likely to experience depression than the general population. If someone is feeling depressed, they may lose interest in sex or they may 'close off' from other people around them.

These emotional changes can be a reaction to the condition and a symptom of MS. It's important that these emotional symptoms, like physical symptoms, are properly recognised and treated. If it's affecting your sex life and your relationship, it can help to talk through your feelings with your partner.

It's also important to remember that if you don't feel in the mood, then it's OK to say no. It might make it easier for them to understand why you may not be interested in sex if they know that depression and other mood changes can be a symptom of MS – and that it's not about them. Equally, talking to your partner about how you're feeling could bring you closer together – which might help with intimacy.

## Fatigue

“ Sometimes when I'm fatigued the effort of putting the kettle on for a cuppa is bad enough without the thought of swinging from a chandelier in a sexy negligee. – Sarah ”

Fatigue can have an impact on libido, and you might feel you do not have the energy or strength for sexual activity. This can be misinterpreted by others – sometimes people say that their partners think they are no longer interested in sex. Being honest and discussing these feelings can help prevent misunderstandings from arising.

MS-related fatigue is typically treated with energy conservation strategies, task prioritisation, balancing rest and activity and possibly medication. If you are prescribed medications such as amantadine or modafinil, it may help to take them just before sexual activity. However, taking these medications in the evening could make it difficult to get to sleep afterwards. Remember to discuss any changes in medication patterns with your doctor first.

If there's a time of day when your energy levels are higher – such as the morning – you might prefer to have sex then rather than in the evening. Planning to rest before and after sex might help too. Why not experiment with alternative positions that are less tiring and require less muscle strain?

## Side effects of medication

Changes in desire, performance and satisfaction can be a side effect of some medications. For example, certain antidepressants, including fluoxetine and sertraline, can affect sexual function and cause problems such as decreased libido, delayed or absent orgasm and ejaculation, and irregular periods.

If you think any of your medications might be affecting you sexually, speak to your doctor or MS nurse about how you can manage this. If you find it difficult to talk to them about sexual issues, there are some tips in 'Talking to health care professionals about sexual issues' on page 14 that you may find helpful.

If you inject disease modifying drugs you may find the injection sites are tender and sensitive, and that you don't like to be touched there. If this is the case, talk to your partner and ask them to avoid those areas. You can also ask your MS nurse about injection technique, to find ways to limit these problems. You might also find that side effects from the drugs, such as headaches, mean that you don't feel like having sex after injecting. If so, you could time your injections for when they're not likely to affect sexual activity. Equally, some people feel such a great sense of relief after their injection that this could be a great time for sex – it's totally up to you.

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## Talking to health care professionals about sexual issues

“ I thought I would die of shame, but she made me feel that it was all normal. She was very matter of fact and somehow it felt alright to talk like that. It was also good that she suggested ways of talking about it with my wife. – Gary ”

It can be hard, and a bit strange, to talk to health care professionals about sexual issues. It's perfectly normal to feel shy or embarrassed. But it's worth trying to talk to them so that they can help you find a solution to any problems.

Most health care professionals should be comfortable discussing how to deal with and treat these sensitive and intimate issues. However, it might be up to you to take the plunge, as some health care professionals can be reluctant to bring up the topic of sexual difficulties with you – they might feel it's intrusive, insensitive, or even inappropriate. They are likely to be full of information once the subject has been broached, though.

There are no 'rules' over whose job it is to talk about sexual problems, so you can talk to whoever you feel most comfortable with. If it's hard to talk to a particular professional you can ask to be referred to someone else. You can use whatever words you feel comfortable using – for example, 'private parts', 'bits', or 'down below'.

You might find it helpful to write down the particular issues you've been having, or any questions you want to ask. That way, if you do get nervous or flustered at an appointment, you don't forget what you wanted to say. You can also ask if there any leaflets or other printed materials you can take away with you, so that you don't have to try to remember everything they are telling you. You could bring this booklet along with you and use it to start the conversation – for example, you could say something like, 'I have read that MS can affect the way I feel about sex, can we talk about it?'

## Lesbian, gay, bisexual or transgendered

If you are a lesbian, gay, bisexual or transgender (LGBT) person, you may find it particularly difficult to talk openly with health or social care professionals about issues of intimacy and sexuality. On top of the difficulty in approaching a subject that's often hard to talk about, you may not be 'out' to your health care team, and may feel forced into coming out to access the services and help that you need. There is often an automatic assumption that people are heterosexual, and this can be tricky to deal with.

There is a dedicated online support group at the MS Society called GLAMS (lesbian, gay, bisexual and transgender people affected by MS) which can provide information and support on this and other issues. For more information on GLAMS call 020 8438 0959 (weekdays 10am-3pm), or visit the message boards on the MS Society website – [www.mssociety.org.uk/forum](http://www.mssociety.org.uk/forum) (look for 'GLAMS').

## Things you can do

“ I have a gem of a husband that I married before MS and when I was diagnosed he said he had married me for the person I am, that he loved me and he wasn't going anywhere. – Sarah ”

As well as talking to health care professionals and managing individual symptoms, there are things you can do at home to reduce the impact MS has on your sexual and intimate relationships.

Some of the tips listed below are for anyone – whether single or in a relationship. Others are for people with a partner, and may help to improve your relationships.

### Tips for anyone

#### Write down how you feel

People often find it hard to talk about sex. Writing down your problems can help to start the communication and identify where the challenges lie. When you are writing, think about which physical symptoms interfere with your intimate relations, or what feelings and associations you have when you think about MS and your sex life. Try to do this at a time of day when you feel relaxed and no-one is likely to interrupt you.

## **Body mapping**

Living with MS can make you feel more aware of your body, how it works and how it does not. When new symptoms appear, your body may feel strange or unfamiliar and it can take some time to adjust to different physical responses. Reconciling yourself with your MS means taking time to investigate and explore how it affects you.

‘Body mapping’ is a simple self-exploration technique. You set aside time and gently touch all parts of your body to identify what results in sensual pleasure, discomfort or sensory change. Allow approximately 15 to 20 minutes each time you do this, and vary the rate, rhythm and pressure of your touch. Ensure you ‘map’ your entire body, not just the areas that are commonly associated with sexual pleasure – and try to avoid reaching orgasm, at least at first.

Through body mapping you can find out what is enjoyable and what causes you discomfort. This is particularly important if you are experiencing sensory changes as a result of your MS, such as numbness or hypersensitivity, which can affect sexual pleasure. You may find your erogenous zones are not necessarily in the conventional places! If you are in a relationship, you may find it helpful and enjoyable to then move on to body mapping with your partner. This can enhance sharing, listening, and overall sensual pleasure, as well as helping to deepen intimate and sexual experiences.

## **Masturbation**

Masturbation can help you discover what is enjoyable for you, especially if you’ve experienced physical or sensory changes due to MS. Solo sex is not shameful, and need not be inferior to partner sex (and many people do not have a partner). You can please yourself and don’t have to worry about anybody else. And spending time exploring your body and what feels pleasurable is also a good training ground for partner sex – if you don’t know what brings you sexual pleasure, it is harder to show a partner what you like.

As with body mapping, make sure you have enough time to explore what you enjoy without being disturbed. If, as a woman, you have difficulty reaching orgasm, remember that feeling ashamed, embarrassed, uncertain or nervous won’t help. Relax and enjoy the sensation – allow yourself to give in to the feelings, and your fantasies. Men should try to avoid getting into the habit of ejaculating as quickly as possible, as you need to be able to control it. Try ‘self-edging’ – bringing yourself close to orgasm, and then pulling back.

MS symptoms such as tremor, pain and spasticity may mean you need to alter the way you masturbate. For example, if you find you don't have enough strength in your hand or arm, then a vibrator can help to do the work for you – of course, you may want to use one anyway.

*The ultimate guide to sex and disability*, available to borrow from the MS Society Library, has more tips for different ways to masturbate.

## **Sex toys**

Many people use sex toys, and they are not rude or dirty. They can help people with MS who are experiencing sexual difficulties – although they are also used by a huge proportion of the general population, too. The kind of toys you choose will be specific to you, and you will find out what works for you by experimentation. You can use most alone or with a partner. They can be bought from both high street and specialist sex shops, many of which have online catalogues. Some specifically market certain products to people with sensory and nerve impairments.

*The sex book* and *The ultimate guide to sex and disability* both contain detailed chapters about sex toys, which you may find useful if you've never thought about using them before.

## **Look after yourself**

Many people with MS say they no longer feel sexy, or think others will not see them that way. Being sexy has a lot to do with feeling sexy. And feeling sexy often relates to looking after yourself – having a good diet, doing some exercise, enjoying relaxing activities and spending time on your physical appearance. Even simple things, like a new haircut, can help.

## **Educate yourself (and your partner)**

There are lots of myths and misconceptions about sexuality, sexual difficulties and disability. Learning more about how MS symptoms can affect relationships and sexual function can often make it easier to understand how you feel and help you discuss problems – if you want to – with your partner. There are self-help books and videos designed to help sexual and intimate communication. You could use them to start talking to each other, for example about whether or not the issues addressed apply to your relationship.

## Tips for couples

“ We’ve always been able to communicate well, so this is just one more thing to learn. I think we’re lucky. I wouldn’t cope as well if we didn’t have the trusting and open relationship that we do. – *Greg* ”

### Communicate

Communication is essential to understanding how MS is affecting both of you. Talking in this way can bring couples closer together, deepen intimacy and help resolve fears. It might turn out that you have both been feeling the same things. When discussing your relationship with your partner, it generally works better if you can avoid accusing, criticising or blaming. Sentences that start with ‘I feel...’ and ‘I would like...’ can be more constructive than those that begin ‘You don’t...’

You might also need to discuss your sexual feelings and anxieties with your partner. It may be that other issues in your relationship have been affecting your sex life – or it could be that the MS itself is changing things for you. For example, intimate things that used to bring you pleasure may now be uncomfortable or painful, so you may need to discuss what does and does not feel good. This involves speaking up about your concerns and needs, as well as being honest about what is and isn’t working. Taking the time to sort through issues will not only help you and your partner to feel more successful in your sexual activities, but should also help you to feel more emotionally intimate as well. Discussing sensitive issues may be very uncomfortable at first, but will get easier over time.

If you have had difficulties communicating for a while, or if your problems are more deep-rooted it can help to get counselling. This might be helpful if, for instance, you or your partner feel frustrated, angry or guilty about caring responsibilities or dependency. You can ask your doctor to be referred, or [Relate/Relationships Scotland](#) can offer affordable therapy to those experiencing problems with relationships or sexuality. [i](#)

### Set aside time

“ I felt selfish for wanting to have some intimate time with my partner when I had carers in and out all the time. I felt I should have been grateful for the help. – *Gail* ”

It can be helpful to set aside time each week to devote to restoring intimacy. Talk about your sensual, sexual and intimate desires and differences. This might be difficult at first, if you have some painful sexual and relationship problems to address. If you are having trouble with this, it may help to 'set the mood': try massage, watching a romantic film together, or making the environment calming and romantic. If possible, keep this time free from caring, parenting and work tasks so you can really focus on each other's needs.

### **Massage and physical contact**

Having physical contact between you and your partner is an important way to create and maintain a connection between the two of you. However, if you have stopped having physical contact then it can be difficult to re-establish that connection.

You could start slowly, by holding hands and hugging, and then perhaps moving on to doing light massage or body rubs (if you are comfortable with it). Using massage oils and playing romantic music can help to create a sense of intimacy and physical closeness, particularly if you're no longer able to have penetrative sex. You could also try bathing together or, if this isn't possible, then you could take it in turns to bathe each other. All of these activities can help to re-establish a physical connection between you, which can enhance your relationship.

### **Changing roles**

If, as a person with MS, your partner is your main care provider, they may find it difficult to shift between the roles of carer and lover. You might also find it difficult to switch from being 'cared for' to lover.

Completely separating caring activities from sexual or romantic activities can help. You might need to develop new sexual signals that help you communicate your sexual desires and needs. You might develop new sexual rituals that fit better with your changing roles in the relationship. For example, your partner could wear an apron when they are doing 'caring' tasks, but when they take it off they are your partner again. A simple trick, but it could be effective. A good way to begin is by discussing your old signals and rituals.

Getting some external support with caring tasks can also help. If there are tasks, particularly those of a highly personal nature, that get in the way of your relationship as a couple, then you can ask social services for paid carers to carry out those tasks.

The MS Society booklets *Getting the best from social care services*, *Getting the best from social care services in Wales* and *Getting the best from social work in Scotland* can all help to identify whether there is any extra support or money you may be entitled to.

It might also help carers to talk to others who are going through a similar situation. The MS Society website has a message board for carers – just go to [www.mssociety.org.uk/forums](http://www.mssociety.org.uk/forums). The organisations Carers UK and Carers Trust also both have online forums for carers, where sex and intimacy are regular discussions. 

## Talking therapies

Counselling from specialist sexual and relationship therapists can help people who are struggling to adapt to, or communicate about, their difficulties. Counselling on the NHS is often limited, but it is still worth asking your doctor. Alternatively, the College of Sexual and Relationship Therapists can advise on private accredited therapists in your area and Relate/ Relationships Scotland offer subsidised advice to both couples and single people experiencing relationship or sexual difficulties. There are also online forums regarding disability and sexuality where you can ask questions and read responses. 

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## Support for partners

“ It can be hard to get your partner to express their feelings. They don't say how they feel because they're afraid of hurting you. – *Liz* ”

If you're the partner of someone with MS, you may have your own fears and concerns. It may be difficult for you to see the person you love feeling unwell, without being able to help them. You want to be able to support them, but you don't know how or if you will be able to. You may have questions about how their MS may affect both them and your relationship in the future. Or you may be feeling angry or sad about the changes that are happening in your relationship or to your plans for your life together – and you may also be feeling guilty for feeling like this.

All of these feelings can have an impact on your sexual and intimate relationships. Much of the information in this booklet can help you to deal with these issues – particularly in relation to communicating with your partner – but you might also find it useful to speak to other partners of people with MS. The message boards on the MS Society website, or the MS Society's Facebook page, offer a way of getting in touch with other partners of people with MS, or you could try contacting your local MS Society branch.

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## Dating and new relationships

“ Love encompasses all you are, including your MS, as that’s a part of you. If it’s a true partnership, you deal with things together. – *Anonymous* ”

If you’re single or dating, MS might raise a number of questions in your mind. When is a good time to tell someone you have MS? Should you tell them? Will they still be interested in you if you do?

Of course, the answers to these questions depend on you and everything going on around you – for example, how obvious your MS symptoms are, or how serious you are about the relationship. In the end, it is your decision whether to tell someone and when to tell them. But you might find it helpful to talk to others who have faced a similar situation, perhaps through online message boards such as the MS Society Facebook page or forums.

When you decide to tell a partner (or potential partner), remember:

- **You are the expert on your MS.** Your partner might have all kinds of ideas about MS that don’t fit your experience – so tell them how it affects you, and how it doesn’t. But equally, you might not be able to answer every medical or scientific question about MS. You may want to give them one of the MS Society’s booklets, such as *What is MS?*, or suggest they visit the MS Society website or contact the MS Society Helpline so they can find out things in their own time.
- **There is no ‘right’ time to tell them.** First dates may be too soon – these are about getting to know someone and deciding if you would be interested in a relationship with them. If you decide that you’re not, then you don’t need to share any personal information. But if you are interested, remember that letting someone know that you have MS doesn’t get easier the longer you leave it.
- **There might be things they don’t want to ask you directly.** It doesn’t automatically mean they don’t care or they’re not interested. They might not want to spend every date asking you questions about MS. After all, there’s more to you than that.
- **You might be surprised by their reaction.** Of course, this is partly why it’s hard to raise the topic in the first place. But it might be a good surprise rather than a bad one.

If you are worried about dating and meeting new people who don’t know you have MS, remember that you can’t decide for someone else if they want a relationship with you. You can only be yourself. Remind yourself that the MS doesn’t define you – it is just one part of who you are. Like everyone else, there are lots of aspects of your life and personality that people are attracted to. It’s true that some people may be put off by MS, but many others will not.

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## Further information

### Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages. For copies, email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk) or call 020 8438 0999.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the librarian on 020 8438 0900.

### Find out more online

Get the latest on research, campaigns, and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

### Join us

Just by being a member you strengthen the voice of all people affected by MS. For just £5 a year you will receive our national magazines – *MS Matters* and *Research Matters* – local newsletters and details of local events, as well as being able to vote on how we are run. Help us continue our vital work and join online at [www.mssociety.org.uk/joinus](http://www.mssociety.org.uk/joinus) or by calling 020 8438 0759.

### Get in touch

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers. Information is available in over 150 languages through an interpreter service. 0808 800 8000 (weekdays 9am-9pm) or [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

### Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

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## Further reading

All these books are available to borrow from the MS Society library. Call 020 8438 0900 or email [librarian@mssociety.org.uk](mailto:librarian@mssociety.org.uk)

***Enabling romance: a guide to love, sex and relationships for people with disabilities (and the people who care about them)*** by Ken Kroll, Erica Levy Klein. Published by No Limits Communications (2001). ISBN: 0971284202. This book is considered the 'Joy of Sex' for people with disabilities. It covers a whole range of subjects and destroys the various sexual stereotypes that exist.

***The ultimate guide to sex and disability*** by Cory Silverburg, Miriam Kaufman and Fran Odette. Published by Cleis Press (2007). ISBN: 1573443042. Self-help sex guide for the millions of people living with disabilities and chronic pain and illness.

***The sex book*** by Suzi Godson. Published by Cassell Illustrated (2003). ISBN: 1844035115. Exploring sex, health and sexuality, this book covers sexual behaviour in gender-neutral, straightforward language, balancing information with practical advice.

***Sexuality and MS: a guide for women*** by Nicki Ward-Abel and Janice Sykes. Published by the MS Trust (2011). ISBN: 1-904156-11-8. Written specifically for women with MS, this book includes suggestions and ideas for addressing sexual difficulties.

***Sex and MS: a guide for men*** by Simon Webster. Published by the MS Trust (2011). ISBN: 1-904156-23-1. Written specifically for men with MS who are worried about sexual issues, and for those who may be sharing sexual activity with them.

***Multiple sclerosis: a self-care guide to wellness*** by Nancy J Holland. Published by Demos (2004). ISBN: 1932603077.

***MS and your feelings: handling the ups and downs of multiple sclerosis*** by Allison Shadday. Published by Hunter House (2007). ISBN: 089793489X.

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# Useful organisations

## **Bladder and Bowel Foundation**

Provides information and support services, including a confidential helpline, for anyone with bladder or bowel problems.

Helpline 0845 345 0156  
[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)

## **Carers Trust**

Information and support for carers. Runs a network of local carers' centres.

Telephone 0844 800 4361  
[www.carers.org](http://www.carers.org)

## **Carers UK**

Help and advice for carers, including a freephone helpline.

Advice line 0808 808 7777  
Advice line (Northern Ireland) 028 9043 9843  
[www.carersuk.org](http://www.carersuk.org)

## **College of Sexual and Relationship Therapists**

Can provide information on common sexual difficulties and sexual and relationship therapy. They also have lists of accredited therapists.

Telephone 020 8543 2707  
[www.cosrt.org.uk](http://www.cosrt.org.uk)

## **FPA (Family Planning Association)**

Information about sexual health, including contraception.

Helpline Northern Ireland 0845 122 8687  
(Monday to Friday, 9am-5pm)  
[www.fpa.org.uk](http://www.fpa.org.uk)

## **Outsiders**

A self-help group for people with physical and social disabilities. It offers members the chance to contact others, gain more confidence, make new friends and perhaps find a partner. Runs the Sex and Disability Helpline.

Telephone 07074 990 808  
Helpline 07074 993 527 (Monday to Friday, 11am-7pm)  
[sexdis@outsiders.org.uk](mailto:sexdis@outsiders.org.uk)  
[www.outsiders.org.uk](http://www.outsiders.org.uk)

## **NHS Choices**

[www.nhs.uk](http://www.nhs.uk)

## **Relate/Relate NI**

Can provide information on sexual health, contraception, sex and relationships and sexuality. Relationships Scotland provides a similar service in Scotland.

(England and Wales)

Telephone 0300 100 1234

[www.relate.org.uk](http://www.relate.org.uk)

(Northern Ireland)

Telephone 028 9032 3454

[www.relateni.org](http://www.relateni.org)

## **Relationships Scotland**

Telephone 0845 119 2020

[www.relationships-scotland.org.uk](http://www.relationships-scotland.org.uk)

## **Sexual Advice Association**

Information about sexual difficulties.

Helpline 020 7486 7262 (Mondays, Wednesdays and Fridays)

[www.sexualadviceassociation.co.uk](http://www.sexualadviceassociation.co.uk)

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## References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, by email on [librarian@mssociety.org.uk](mailto:librarian@mssociety.org.uk), or visit [www.mssociety.org.uk/library](http://www.mssociety.org.uk/library)

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Suggestions for improvement in future editions are welcomed. Please send them to [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

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The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

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## MS Society

100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

The MS Society is the UK charity fighting to improve treatment and care to help people with MS take control of their lives.

We're a world-leading funder of MS research. We've already made important breakthroughs, and we're now at the start of a generation of MS research that holds incredible promise.

With your support, we will beat MS.

## Contact information

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372 Edgware Road  
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info@mssociety.org.uk

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Newbridge EH28 8PP  
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msscotland@mssociety.org.uk

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Telephone 028 9080 2802  
information@mssociety.org.uk

MS Society Cymru  
Temple Court  
Cathedral Road  
Cardiff CF11 9HA  
Telephone 029 2078 6676  
mscymru@mssociety.org.uk

MS Helpline  
Freephone 0808 800 8000  
(weekdays 9am-9pm)  
www.mssociety.org.uk

Online  
www.mssociety.org.uk  
www.facebook.com/MSSociety  
twitter.com/mssocietyuk

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