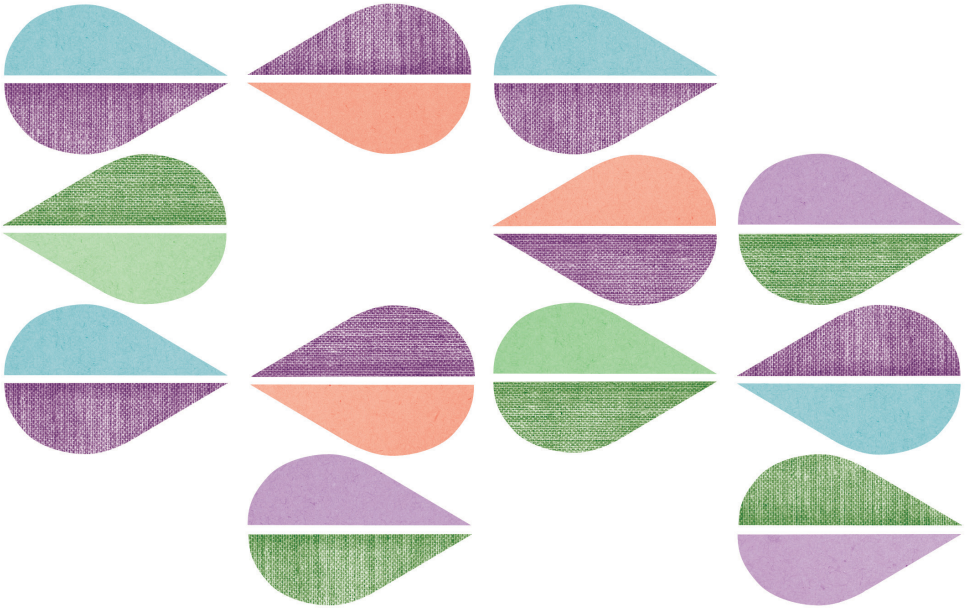
Sex, intimacy and MS:

A guide for WOMEN



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Introduction

This book was first published in 2007. Since then, society has become increasingly aware that gender identity exists on a spectrum rather than being binary (female/male). 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 women (females who identify as women), this book may also be relevant to individuals who identify as non-binary who were assigned female at birth, and some trans(gender) men and trans(gender) women – depending on whether they have chosen to have gender-affirming surgery.

Whilst we continue to predominantly refer to women 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.

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

Everyone's sex life is unique, this book is for you whatever your sexual orientation, sexual identity, sexual preferences, or relationship status – be that single, 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 not everyone with MS finds that their sex life is affected and that not all concerns about sex may be due to MS. It may be that not all the information in this book will be relevant to you personally – choose the sections which are meaningful for you.

The book looks at how MS can alter your sexual response and offers some suggestions for coping with symptoms that may affect your sex life. 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.

If you're in a relationship, your partner(s) may also be affected, so we've included a section for them. It may help them better understand what you're experiencing or feeling, so you can share any concerns and work together towards finding ways around them.

Although you may find it daunting to talk about sex, there is lots of help you can access online or through professionals, so we look at some ways to try and make it easier to raise the subject with partners and the health professionals involved in your care. There are also details of further sources of support.

The information in this book will by no means cover every situation you may come across. 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

1. The sexual response

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.

Generally, arousal begins in the brain. Depending on your preferences it can be stimulated by just about anything – reading erotic material, seeing sexual images, recalling previous encounters, or picturing your sexual fantasies – pretty much whatever it is that turns you on.

The brain processes these messages and relays them to the sex organs through the nerves in the spinal cord. Other parts of the body are also involved, such as the circulatory system, with the heart rate rising and increased blood flow to your sex organs. Also, your breathing rate tends to speed up.

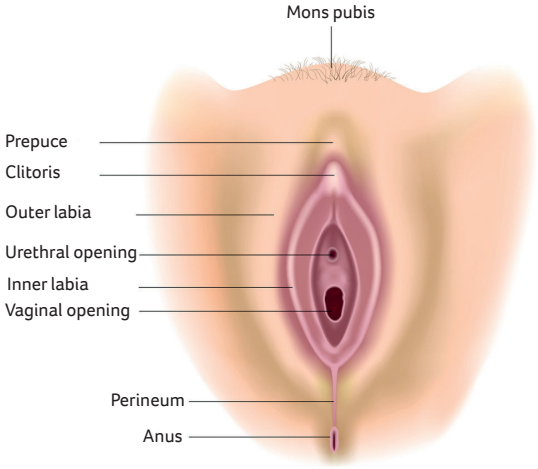
Phases of the sexual response cycle

Sexual interest or desire. Desire, or your libido or sex drive, is an important part of your sexual response. The way you feel sexually is very connected to your state of mind and a whole range of mental factors can affect your level of desire – the brain has even been described as the most powerful sex organ! Self-esteem, how you (and your partner) are feeling in terms of your mood, stress levels or how you're feeling towards each other at any given time are important. Physical factors also have a role – confidence in your own physicality, trust and feeling safe to engage in sex or play out fantasies, or being able to share what turns you on and what you find pleasurable (or not) all play a part.

Although you may not initially experience desire, you can still respond to and enjoy intimacy or sexual activity.

Arousal. Desire is accompanied by an increase in blood flow to your genital area as you become aroused – particularly to the clitoris in those with female genitalia. The clitoris is found at the top of the

vulva – the external genitalia, which also include the mons pubis (or pubic mound) and labia (the tissue or lips that surround the entrance to the vagina) – and extends deep into the body to the entrance of the vagina.



Your clitoris responds to touch and stimulation by swelling with blood and increasing in size. This is followed by the swelling of your labia, your labia open slightly, and your vagina elongates and balloons at the top. At the same time, your vagina produces more lubrication allowing easier and more comfortable access for the insertion of fingers, a sex toy or penis. The amount of lubrication you produce does not necessarily reflect your level of arousal or desire. There is also an accompanying increase in blood flow to your breast tissue, which can enlarge slightly, the veins become more visible, and your nipples may become erect.

Orgasm. As you become more aroused, there's an increase in energy within the nerves and muscles in the body – especially around the genital area and anus – and this causes the muscular contractions that may lead to orgasm. For most women, whether you orgasm or not can be a bit hit or miss and only a small proportion of women say they always climax during sex with a partner, and some never do.

There can be lots of things that influence whether you orgasm or not – it can vary depending on where you are in your menstrual cycle, the pressure or rhythm of stimulation might not be quite right, or mentally

you might not be in the right frame of mind. Most women require some degree of clitoral stimulation to climax, very few do through vaginal penetration alone. If you're feeling tired, stressed, or unhappy in your relationship this can also impact on your ability to orgasm.

It's important to remember that sex can be very enjoyable even without having an orgasm – feelings of intimacy and being aroused are still pleasurable.

Resolution. During this phase, your heart rate and breathing return to normal levels, blood flow to the genitals decreases and swollen tissues return to their usual size and colour. Often this phase is accompanied by a sense of wellbeing, and you may feel fatigue.

Factors that can influence the sexual response

Your sexual response is shaped by many things, including hormonal changes that may be influenced by factors such as what point you're at in your menstrual cycle if you have periods, pregnancy, menopause or if you're taking any form of hormone therapy – including contraceptives for birth control.

We all react differently to hormonal changes, and you may find that your thoughts and feelings towards sex change at various times of the month and at different stages throughout your life. For example, if you have periods, desire tends to increase in the days leading up to ovulation and then decrease shortly afterwards.

Contraceptives such as the combined pill, vaginal rings and hormonal patches contain a combination of oestrogen and progestin in varying amounts. Whilst the mini-pill, implant, and injectable shot, only contain progestin. Research into the effects of hormonal contraceptives on sexual desire has been mixed – with some studies finding no effect, others finding participants had reduced desire and some concluding users had increased desire. This variation shows just how personal any one individual's response is to changes in hormone levels.

During pregnancy, higher levels of sex hormones and increased blood flow to the genitals occurs, which can lead to heightened desire. However, the physical changes, nausea and fatigue that accompany

pregnancy may result in reduced desire particularly during the first and third trimester.

If you're experiencing perimenopause (the years leading up to menopause) or menopause, there are several reasons why you might experience reduced sexual desire. These include emotional changes; reduced levels of sex hormones result in less blood flow to the genitals which can make it harder to become aroused, vaginal dryness can make penetration uncomfortable or painful, or symptoms such as night sweats can affect sleep and leave you with less energy.

However, you may find you feel a greater sense of freedom post-menopause, for example you're no longer concerned about becoming pregnant, are more comfortable in your own skin as you age or have less family responsibilities. These factors may mean you find your sex drive improves.

If you're menopausal you may choose to take hormone replacement therapy (HRT) to alleviate some symptoms such as vaginal dryness, hot flushes, night sweats and mood changes. Typically, a combination of oestrogen and progestogen is taken. HRT may also help with a reduced sex drive.

Steps in the transitioning process can affect desire in transgender people. If you're a transgender man (assigned female at birth but identify as male) you may receive hormone treatment with testosterone, this can lead to an increased sex drive – particularly in the first few months of treatment – which then tends to stabilise.

Oestrogen and anti-androgens may be prescribed if you're a transgender woman (assigned male at birth but identify as female), this may lead to a temporary reduction in desire when you start treatment which then returns to previous levels after a few months.

Hormone therapy in transgender people may also improve mental health and wellbeing which can also have a positive impact on sexual response.

Many symptoms that are associated with hormonal changes, including fatigue, altered mood and problems with memory and concentration can also be symptoms of MS. This means it can be difficult to determine whether changes to your symptoms indicate a

possible worsening of your MS or are due to changes in your hormone levels at certain points in your life. Speak to a health professional if you're not sure.

External factors and pressures in life can greatly influence your level of desire – who you're with, the circumstances, and stress, fatigue or any distractions all play a part. These pressures are often transient and so can change from moment to moment.

'Sexuality' can be a difficult term to define and is often thought of simply in terms of sexual orientation. However, our sexual identity is much more than this and is unique to each of us. Sexuality can encompass how you express your sexual identity, how you feel about yourself, and your sense of self-worth or self-image. It influences the way you present yourself to, and communicate with, others including your partner(s) or potential partners.

Your personality, background, lifestyle, cultural and/or religious beliefs all help shape your sexuality and will influence your sexual response at any given time. Previous sexual experiences and your individual preferences also have a role. Your sexuality goes far beyond your ability to engage in, and enjoy, intimacy and sexual activity.

2. MS and sexual response

Having MS may not change the way you respond sexually at all.

However, there are things that may alter your sexual response that can be influenced by MS. It's important to remember that many women who don't have MS also experience some of the issues described here – they can be a natural part of life, not just a consequence of MS.

Sexual issues can occur at any time during your life with MS and may have been present before diagnosis. They can come and go or may be more constant. They could be due to other health issues which aren't connected to your MS. There's no way to predict whether your sexual response will be affected, but studies suggest as many as 80% of women with MS report concerns at some point compared with up to 50% of women in the general population.

Issues may occur if you have MS lesions in the brain or spinal cord in areas that influence your sexual response, or in areas that result in symptoms that can affect how you respond sexually – for example, if you have altered sensations and experience hypersensitivity or reduced sensation this can alter how you react to touch. The gentlest of strokes may feel unbearable or conversely you might find you need a more intense pressure for stimulation than previously.

Any changes you do encounter won't necessarily be related to the length of time you've had MS, or any physical limitations MS brings. However, we do know if you have lesions in your spinal cord and have walking and/or bladder problems you're more likely to experience sexual issues, as the nerves that control walking and bladder function are found near to those that lead to your sex organs.

There are many medications which can affect sexual response, so some medications you're being prescribed for MS, or other coexisting health conditions, could potentially impact on your sexual response.

The emotional, psychological, and cultural consequences of living with MS can also alter how you feel and respond to intimacy and sex. Even if you would like to have an active sex life, you might find that your psychological state is preventing you from engaging. Your body might be telling you yes, but your mind is saying 'Are you sure?', or 'You're tired, you can't' and you listen to this inner voice and give up on the idea – in the same way that you might talk yourself out of exercising for similar reasons. Physically nothing is stopping you, but having MS can make you more analytical of your body and how you're feeling, and you can sometimes make wrong assumptions about what you want and are capable of.

For many of us, our sexuality is an important part of our identity. If you've always considered yourself a very sexual person, enjoyed an active sex life, with a strong sex drive and intense orgasms it can be upsetting if things change, no matter whether this is due to natural fluctuations in your hormone levels, altered sensations, illness or as a side effect of medication.

Losing your identity as a sexual being can be hard to accept. It's not unusual to experience feelings that are associated with bereavement such as sadness, anger, or grief for the loss of your sensual self. This sense of loss may also affect your partner(s) as they adapt to any changes in your relationship. Communication is key – sharing your concerns and how it's affecting you both can help avoid feelings such as rejection, guilt, or frustration.

How can MS alter your sexual response?

The physical side of becoming aroused begins in the brain where any erotic stimulation is processed – be that sexual thoughts, images, or touch. The brain relays these messages to your sex organs via the nerve pathways in your spinal cord. MS lesions can damage the nerve pathways involved, for example, lesions in your spinal cord can lead to reduced sensation in your clitoris and vagina, whilst lesions in the brain may affect desire.

There are several reasons why you might experience a change to your sexual response when you have MS, and they could affect your ability to enjoy sex as much or make it more difficult to climax. These include:

- loss of desire (libido)
- vaginal dryness
- loss of sensation
- hypersensitivity
- fatigue
- pain
- spasticity
- bladder and bowel problems
- mental health issues such as anxiety or depression.

Loss of desire

A lack of interest in sex is an issue for many women, not just those with MS, with an estimated several hundred thousand women in Britain affected at any one time. This is because desire naturally fluctuates over the years – this might be due to the point you're at in your relationship (new versus longer-term) or to major life changes such as pregnancy, menopause, or illness.

MS can affect your sex drive in two ways:

- directly – because of the location of lesions in your brain
- indirectly – if you're feeling anxious, fatigued, have experienced a loss of self-esteem, or as a side effect of medication.

You may be reluctant to initiate sex, or respond to sexual advances, if you're experiencing a lack of desire. But a lower sex drive doesn't necessarily mean that you can't become aroused or climax if you do engage in sexual activity. Sometimes it can be worth giving it a try even if you don't feel 100% in the mood. Although it may feel a bit forced or lack spontaneity at first – who knows where it might lead?!

However, it's important to remember that in a healthy consensual relationship both you and your partner(s) should feel comfortable with the level of physical intimacy in any encounter, and you should never feel obliged or forced to do something you don't want to. If someone is persistently pressuring you, or trying to guilt or shame you to engage in sexual activity that you don't want to, this is known as sexual coercion. Coercion can be quite subtle; it may be verbal or emotional but in some cases it is physical. If you're concerned that you're in a coercive or abusive relationship, there are details of some organisations that can support you in Section 8.

If you are happy to give it a try, the following are some ideas that might help when you're not entirely in the mood for sex. Remember, the act of having sex can increase your sex drive – due to the release of feel-good hormones such as oxytocin and serotonin, and you always have the option to stop at any time if it's just not working for you or your partner(s).

Make time for foreplay. Sex is much more enjoyable if you're fully engaged in the act. Try focusing more on your senses as this can lead to greater satisfaction – this applies to your partner(s) too. Expressing your affection for each other and taking time to enjoy exploring each other's bodies can help create the right mood. Section 8 of this book has some fun ideas for some games you could try.

"I have very little sensation in my genital area, but I can still become aroused if my partner takes their time and I really enjoy the intimacy."

Set the scene. Consider what will turn you on mentally and help you relax physically. This might include creating a sensuous environment by taking a bath or shower together, lighting scented candles, playing soothing music or using aromatherapy oils to massage each other. Try to make sure you won't be rushed or disturbed.

"It was worth the embarrassment of telling my partner what I really enjoy. Now he really knows what turns me on!"

Relax. This can be easier said than done, but stress and tension can clearly impact on your level of desire. Some people find a glass of wine, or a warm bath helps them relax – but for some people with MS

this can exacerbate fatigue. If fatigue is an issue, measures such as listening to music or some simple breathing exercises might help you wind down and feel more in the mood.

If stress is an ongoing issue for you, you could try a relaxation CD, or a mindfulness or meditation app. These can you teach you more advanced breathing exercises or self-hypnosis techniques which might help reduce your anxiety. Techniques such as body scanning, visual imagery and positive self-talk meditation can also help reduce anxiety and tension in your muscles.

Indulge your fantasies. You may find fantasising helpful. You probably have your own personal fantasies – you may be fine sharing them with your partner(s), but some people prefer to keep them to themselves. For this you really need to think about what turns you on. It could be imagining having sex in a romantic location such as a deserted beach, or a public place where you might get caught in the act, having food licked off your body or using sex toys, dressing up or role-play. Common fantasies include picturing having sex with someone, or in a way, you wouldn't usually – this might be visualising someone who isn't your partner such as a work colleague or a celebrity, or someone of a different gender than you're usually attracted to, with multiple partners, or in a position you've never tried.

The only limits are your imagination, but if you are struggling a bit there are erotic novels and films available that could help you visualise ideas that work for you. Who knows where your mind might take you!

"We share our fantasies more now that we are older and more comfortable with one another. This has led to us enjoying oral sex more."

Get in touch. Touch can be very therapeutic and it's a good way to restore or maintain intimacy if there are times when some sexual activities you enjoy aren't possible or what you want. You may find touch is too uncomfortable or even painful if you experience hypersensitivity and this is considered later in this book. If you are ok with touch, stroking and exploring yourself on your own or together with a partner can help re-establish desire, bring you closer together and enhance feelings of tenderness.

Try not to focus on your genitals or chest too much at first – find other areas that also give pleasure. This might be being stroked gently behind your ears or the inside of the wrist, having your feet, scalp, or neck massaged, or a finger trailed slowly across the collarbone. You could think about introducing different textures to stroke with, such as feathers or a silk scarf, or using massage oils to discover the most pleasurable sensations or intensity of pressure.

"Having my partner massage me gently beforehand helps me get in the mood more, either using a scented or plain oil."

Explore your body. Body mapping (or sensate focusing) is a simple technique that you can use on your own or alongside a partner to increase intimacy and rediscover sexual pleasure. It involves exploring your body to find out exactly where touch gives you pleasure or discomfort. If you decide to give body mapping a try it's best to find somewhere that you feel relaxed and won't be disturbed for at least 15-20 minutes. Then take off your clothes and lie down.

Body mapping exercise

1. It can be useful to draw a basic map of your body – you can use the one on page 18 if you want. You might want to make copies as it can be useful to carry out this exercise more than once as your preferences might change at different times – areas that felt pleasurable one week may be overly sensitive a week later.
2. Systematically take time to touch different areas of your body from head to toe – or as far as you can reach. You could do this yourself or get a partner involved, you can always reciprocate for them later. If you are doing the exercise with a partner, you could always place your hand over theirs to help guide them. Think about how it feels to be touched in each place, whether it gives you pleasure, or causes less enjoyable sensory changes and note it on the map. If you're doing this with a partner describe what you're feeling and get them to write it down. Make sure you map your entire body, not just the obvious areas – you may find you have erogenous zones that you weren't expecting!
3. You could give different areas a score on the map, for example: 1. Very pleasurable, 2. Pleasurable, 3. No sensation, 4. Uncomfortable, 5. Very uncomfortable, 6. Painful.

Alternatively, you could create a colour code, for example red for areas which are a definite no go, yellow for areas where it depends on how you're feeling or the situation, and green for areas that give you intense pleasure or arouse you.

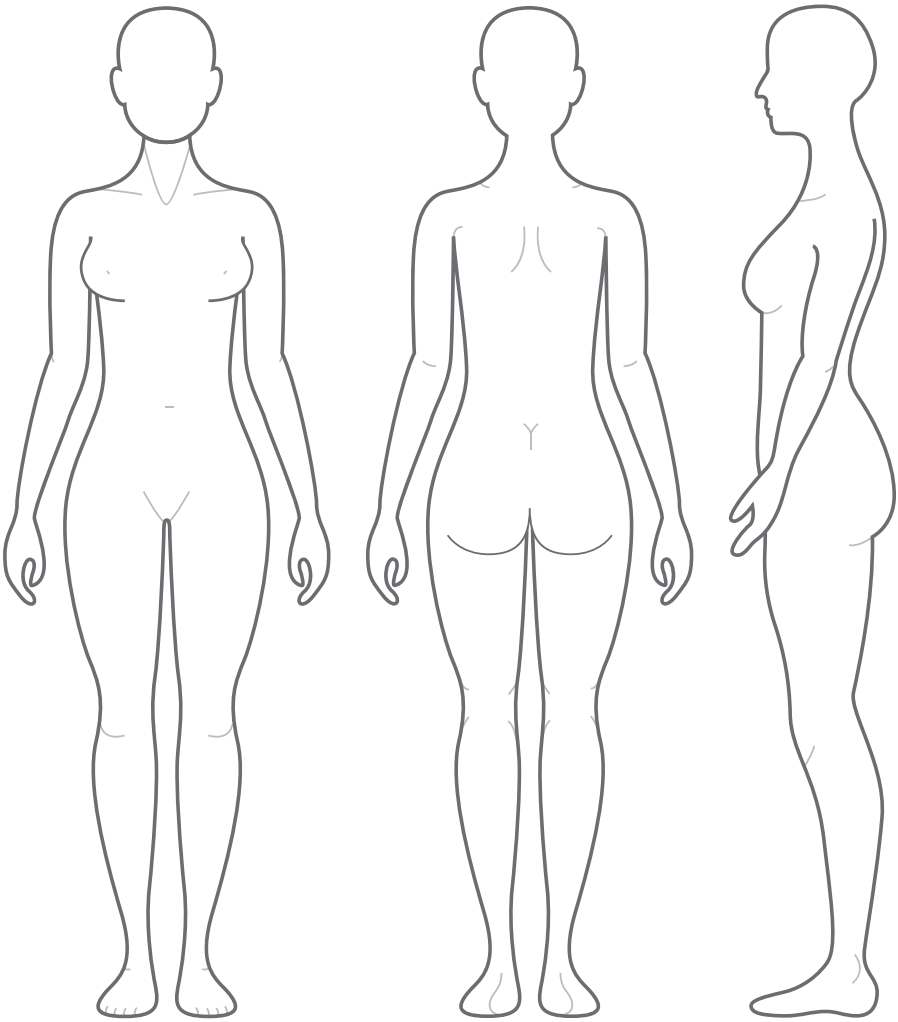
For each area think about the following.

- What level of pressure feels best? In some areas it might be a simple light brush whereas other regions may need a firmer touch or degree of pressure.
- What motion feels most pleasant – being stroked in the same direction, up and down, or perhaps a circular motion?
- What speed or rhythm works? You may initially prefer a slower, lighter touch that becomes faster or more intense as you become more aroused.
- What do you like to be touched with? Fingers, other body parts, feathers, silk, a soft brush, leather, or vibrating toys are all things you could explore using.
- Different temperatures – perhaps you like the cold sensation of an ice cube being trailed over your body, or a tingling or warming massage lube.

Remember the aim of the exercise isn't to reach orgasm, in fact it's usually recommended that you don't attempt this initially as it can defeat the purpose of the exercise.

As you become more experienced about your likes and dislikes you might find you no longer need the maps. However, they can be a good reminder of how your touch preferences change based on where you are emotionally, where you are in your sexual response – be that unaroused > aroused/excited > at climax > post-orgasm/resolution, any medication you've taken or when symptoms change.

Female body map



Psychological barriers. If you're feeling anxious or depressed this can alter how you identify and respond sexually. You may experience a sense of guilt if you don't feel you're fulfilling the role you want in your relationships. It can be difficult to identify what you're feeling in these circumstances and psychotherapy, or relationship counselling can be beneficial if you feel you need support in exploring these kinds of issues. There is more information on how to access these services in Section 8.

Vaginal dryness

A lack of natural vaginal lubrication can make penetration of the vagina uncomfortable or painful; even touch may feel less pleasant. Dryness can be caused by several factors, many of which aren't related to MS at all, for example hormonal changes at the time of menopause, dehydration, or some medications. There are vaginal moisturisers available such as Replens and Sylk which are helpful for relieving dryness. Vaginal dryness can put you at increased risk of developing urinary tract infections, so spending more time on becoming aroused, for instance by focusing for longer on foreplay, may help you become more lubricated and reduce this risk.

Vaginal lubricants can also be helpful to overcome dryness during sex and using them may have the additional benefit of increasing sensation in your genital area as many are formulated to produce warming or tingling sensations. Water-based lubricants such as KY jelly, Sensilube and Astroglide are usually inexpensive and are preferable to oil-based lubricants which can damage condoms, stain fabrics and don't flush out of your body as easily – which can increase the risk of infection. However, water-based lubricants aren't effective in water and can feel slightly sticky so they're not for everyone. There are a wide variety of lubricants on the market, so it's worth trying a few to see which work best for you. Apply them liberally and use more as needed – once applied their effects can be boosted with water or saliva.

Loss of sensation

If you've experienced a loss of sensation in your genital area, it's likely you'll need more intense stimulation to be able to climax. It's worth remembering that sex doesn't have to (and rarely does) result in an orgasm every time and climaxing at the same time as your partner is relatively rare. Sex without an orgasm can still be extremely pleasurable, but if you want to try some things to see if you can climax more often the following may help.

Masturbation. Being aware of what turns you on and gives you pleasure makes it more likely you will be able to reach orgasm and enables you to share your preferences with any partners too. Masturbation is a good way to discover what gives you the most enjoyment. You could use your fingers, or experiment with a lubricant, finger vibrator (this is worn on your finger like a ring or thimble), or other vibrator to intensify the stimulation. As with the body mapping exercise, you could also try using other textures such as silk, fur, feathers, or something with a rougher texture like a brush.

Find somewhere comfy where you're not going to be disturbed. Decide whether you'd rather keep your clothes on or undress – some people enjoy the added friction that masturbating through clothing can add, whilst others prefer direct skin contact. Then slowly start by exploring your nipples before moving on to your genital area. Vary the pressure, intensity, and rhythm of your touch to see what works best and what doesn't do it for you.

Oral sex. Many women find they climax through oral sex more easily than penetrative sex. This may be something to explore if you've not tried it before and feel comfortable with the idea, or revisit if it's something you've enjoyed in the past – perhaps start with fleeting kisses or gentle probing with the tongue in the genital area to see how it feels and go from there.

Fantasising. Remember we said the mind is one of the most important sex organs? Why not make the most of it? Incorporating fantasy into your sex life may help you reach orgasm more easily.

Try a vibrator. You may find it easier to climax if you use a vibrator, as it can often compensate for any loss of sensation and intensify any feelings that are still present. Vibrators come in many different shapes and sizes. Some are designed simply to stimulate the clitoris, for example bullet vibrators, which can be a good place to start if you've not experimented with sex toys before. Others can be used in and around the vagina or anal area, and some include thrusting motions for penetration.

Vibrators come with variable speed and pattern settings, usually within the same model – mains operated vibrators tend to be more powerful than battery operated ones. You may find you need to use quite a vigorous setting, although it's probably best to start on the lowest setting and work your way up.

Vibrators can be bought from some high street stores and supermarkets, or there are lots of online suppliers if you prefer a more discreet approach (see Section 8). Most online suppliers have a guide to help you find what you're looking for if you're not quite sure where to start. Or you might prefer the option of a party where you can check out the products that are available in the comfort of your own (or a friend's) home.

"In order to reach orgasm, I have to use a vibrator. It was a partner who suggested it and I was very embarrassed at first, but it's brought an added dimension and creativity to sex! I would urge anyone who is having difficulty in reaching orgasm to invest in a vibrator! Don't be embarrassed about it – stores sell loads of them, so it's not anything out of the ordinary anymore. My partner finds it very erotic and often wants to take charge!"

Anal stimulation. This isn't for everyone, but if you are open to trying it, the anus has lots of nerve endings. Touching in and around this area and the perineum (between the genitals and anus) can create pleasurable sensations which may lead to orgasm.

Other tips for reaching orgasm

- Hormonal changes can affect your ability to climax; experiment to discover the best time of the month for you.
- Try panting whilst having sex – although don't do it for too long as it can make you lightheaded!
- Carrying out pelvic floor exercises can improve the tone of the muscles of the vaginal wall – this may enhance your ability to orgasm.
- Raise your pelvis by placing a pillow under your hips as this can allow for easier and deeper penetration – some websites sell specially designed pillows or wedges, but you can use an ordinary pillow too.
- Hang your head over the edge of the bed when having sex – the extra blood flow to the brain is thought to help heighten your sense of pleasure.
- Lying across the bed with your legs hanging over the edge of the bed allows for easier access to your clitoris and vagina.
- Experiment with different positions if you can – some may work better for you than others.

"It may sound simple, but now we always make love with the lights on. I can watch my partner as he touches me, watching him makes me feel really sexy and I like this."

If these suggestions don't help, you might want to consider seeing a sex or relationship counsellor for more help or practical tips. Don't regard needing counselling as a failure – it's a positive move that can be helpful for many relationships. A sex therapist or counsellor may be able to prescribe treatments or other ways of managing problems that aren't routinely available (see Section 8).

Is there a female equivalent to Viagra? In the UK, there are currently no medications licensed for women to help with a decrease in sexual interest, or the ability to become aroused or reach orgasm. There has been research on the effects of Viagra and other similar drugs in women, but they weren't found to help. Although these drugs can help achieve an erection, they're not an aphrodisiac and don't influence desire, arousal, or orgasm – which is probably why they don't work in women.

A treatment called flibanserin (Addyi) has been licensed in the United States for premenopausal women experiencing low sexual desire, although its approval has been controversial. It was originally developed as an antidepressant. It is taken daily as a pill and acts on the areas of the brain involved in thinking and emotions. It alters the balance of neurotransmitter chemicals towards sexual excitement and away from inhibition. However, the evidence for its use is not strong and only points to a small increase in sexual activity in those taking it. Side effects include low blood pressure, dizziness, nausea, sleepiness, and fatigue. It can't be taken with alcohol or grapefruit juice.

A second treatment, bremelanotide (Vyleesi), has also been approved in the USA. This is an injection designed to improve sex drive in premenopausal women, which is administered in the thigh or abdomen at least 45 minutes before any anticipated sexual activity. It's thought to work by altering the pathways that contribute to sex drive and arousal. Side effects include nausea, vomiting, flushing, headache and skin reactions at the injection site.

There is ongoing research in this field to find additional treatments. For example, researchers at Imperial College London are carrying out research on kisspeptin, a naturally occurring hormone which stimulates the release of other reproductive hormones in the body. Their most recent study included 32 premenopausal women with low sexual desire that was distressing to them (known as hypoactive sexual desire disorder or HSDD).

Kisspeptin was administered via an intravenous infusion and was shown to improve sexual and attraction brain processing leading to positive effects on sexual desire and increased responses to sexual stimuli (viewing erotic videos) compared to placebo. Kisspeptin was

found to be safe, and no notable adverse effects were identified. The researchers are planning to do further studies in people who experience sexual issues which are psychological in origin, such as unexplained low libido.

Despite promising research, it's important to remember that issues around desire, arousal and orgasm are complex, and even the best medications may not work if there are other unresolved emotional or social factors.

Hypersensitivity (dysaesthesia)

This is where your skin is so sensitive that even the gentlest of touches can be uncomfortable.

"I suffer from dysaesthesia, and I often have to tell my partner that something isn't comfortable – even being hugged can hurt me sometimes. I need to explain that this is normal for me and that what I enjoy sexually changes from day to day."

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

The body mapping technique outlined earlier 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 – you might have to experiment a bit to see if it can be of any benefit.

It's normal for your sexual response and the intensity of any orgasm if you do climax to vary from one sexual encounter to another. However, if you experience hypersensitivity any sensations, including heightened orgasm, can feel overwhelming. If you find 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 a partner:

- talking dirty 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.

Fatigue

Feelings of tiredness or exhaustion are highly prevalent in the general population due to our busy lives, but the neurological fatigue that is commonly seen in MS is very different to this and can be debilitating. If you're experiencing fatigue, sex is probably the last thing on your mind and as a result, you might find yourself shying away from any form of intimacy in case it leads to sex. However, remember sex can be a form of relaxation and the endorphins that are released during sex can help boost your mood and energy levels.

If fatigue is an issue for you, and you feel it's impacting negatively on your sex life, consider the following.

- When do you have the most energy? This is quite often in the morning, so it might be the best time for you to have sex.
- Experiment with different positions – some require less energy than others. One option is to try 'spooning' where you lie side to side with your partner so you're not having to support your own or their body weight – your partner can also easily reach your clitoris. Penetration can be from behind in this position.

- Try masturbation (solo or mutual), foreplay or oral sex if you're particularly tired.
- Take a rest or try a cool, invigorating shower before sex.
- Try the 'stop, start' technique – this involves taking a break when you start to tire and then starting again. The break might only last for a few minutes or so you can change position, but it can allow you to recover. It may even tease your partner and add to the excitement.
- Remember that a quickie can be great fun and still as satisfying!

Spasticity

Spasticity can make it challenging to find a sexual position that is comfortable. If your legs are inclined to clamp together with the minimum of stimulus it can make things particularly tricky. You might have to be a bit more imaginative and try different positions that don't trigger spasms if you want to be able to have your clitoris stimulated or be penetrated. Things like standing whilst leaning against furniture, lying on your side or on top of your partner are positions to try.

The following are some tips for minimising spasticity.

- The right position is key. Spastic movements are often triggered by lying flat on your back with your legs stretched out, so avoid this position if it's an issue for you.
- Once you've found a position you find comfortable, try to identify any movements that trigger spasms or other unwanted movement so that you can aim to avoid them.
- If you are lying on your back try using pillows under your knees or bottom, or a rolled-up towel in the small of your back. These can all help reduce the risk of spasm; they also have the bonus of making it easier to reach your genital area and may allow for deeper penetration. There are specially designed cushions and wedges available which may help you find the best position (see Section 8).
- If you're taking anti-spasticity medication, ask your GP or MS nurse if you can increase the amount you take before sex.
- Using massage and relaxation techniques prior to sex can help relax the spastic movement.
- Try exercising your limbs gently prior to having sex, this is something you could get a partner to help with. Your physiotherapist or MS nurse can advise you about suitable passive movements.
- Finally – relax and trust your partner.

"I find lying on my back clutching a knee with each hand towards my shoulders works. My knees must be bent right up to break spasticity. This position also means I can have lazy sex when I'm knackered!"

Bladder and bowel problems

Lots of women in the general population leak urine when they orgasm – and some partners find this a turn on. However, if you experience bladder and/or bowel problems it can be a source of great anxiety when it comes to sex and wanting to be intimate. Worrying that you might lose control of your bladder or bowels during sex, means you might choose to avoid it altogether as the embarrassment would be too great – especially if you're with a new partner. Talk to partners about your concerns, it can be therapeutic and can clear up any misunderstandings about why you're avoiding intimacy.

The following are some practical tips.

- Seek the advice of a continence specialist – you can be referred by your GP, MS nurse or neurologist, with some services allowing you to self-refer. They can carry out an assessment and may be able to suggest helpful strategies.
- Be aware that urine infections, which are generally more common in women, can cause incontinence and may be aggravated by vaginal dryness and sexual activity. If you suspect you may have a urine infection or are experiencing repeated infections, see your GP.
- Emptying your bladder prior to sex may put you more at ease, it's also a good idea to go again shortly after having sex to minimise the risk of infections.
- Sometimes limiting your fluid intake for a few hours prior to sex helps – this reduces the amount of urine produced by your kidneys but be aware this leads to more concentrated urine which can increase the risk of incontinence. So, this strategy isn't for everyone and shouldn't be something you should do on a regular basis.
- Put protection such as towels or disposable bed pads on the surface where you're having sex. It doesn't take the problem away, but it might help you relax a little.
- Self-catheterisation using an intermittent urinary catheter prior to sex can be helpful.

- If you use an indwelling catheter, which is inserted in the same way as an intermittent catheter but left in place, you could try different positions to reduce the risk of dislodging it – spooning can be a good option. You can also empty the bag and temporarily clamp off the drainage tube. Taping the tube to your abdomen or wearing a pair of crotchless pants can help keep it out of the way.
- Suprapubic catheters enter the bladder through an incision in the abdomen, this means the catheter is positioned away from your genitals, so it's less likely to get in the way when you're having sex. This may be a good option if you find sex with an indwelling catheter uncomfortable.
- If you're worried about losing control of your bowels, this can be managed by opening your bowels before sex, using a micro enema if necessary. There are also transanal irrigation systems available, such as Peristeen and Qufora, which can be used to empty your bowels. If these methods aren't an option, or if continence remains an issue, you could consider using a temporary anal plug. All these options can help give you confidence that you're not going to have a bowel movement in the heat of the moment.

Micro enema

Anal plug

Peristeen

Finding the best sexual position

Experimenting with different positions and varying your sexual routine can be invigorating, and a lot of fun! Be bold. There are lots of books and information online that can help you find different ideas to try. Be prepared to be adventurous and perhaps go outside your usual comfort zone. Also, remember there are plenty of ways to achieve pleasure both with and without penetration.

"My stamina is a lot less now and I can't sustain any actions for any length of time as bits of me tire out. I need to change position a lot – although generally there aren't any complaints about this!"

"I get tired quicker and find some positions impossible now. We've had to adapt and experiment with new ideas and positions. Kissing and cuddling have become an important part of our relationship and something I really enjoy."

The most important thing is to have fun and enjoy yourself. Not all your experiments will work out quite how you thought, but you can always laugh together about the things that didn't quite go the way you expected or have the desired effect!

Medication and sexual response

There are many classes of medication that are known to affect your sex life. Some can lead to vaginal dryness; others cause a decrease in desire or difficulties in achieving orgasm. They include:

- antidepressants – block the effects of chemicals that relay signals between the nerve cells
- antipsychotics (sometimes used to treat depression) – block dopamine which regulates emotional responses and controls the pleasure centres in the brain
- benzodiazepines (used to treat anxiety and muscle spasms) – have muscle relaxant properties which can reduce desire, affect arousal, and reduce sensation
- anticonvulsants (which can be used to treat neuropathic pain) – can cause lubrication problems and impair orgasm
- treatments for high cholesterol (such as statins) – can affect the production of sex hormones
- blood pressure medications – the reduced blood flow they achieve can affect lubrication, desire, and orgasm.

Many of these medications are prescribed to manage MS symptoms and so have the potential to impact on your sexual response. Perhaps some of the most widely prescribed treatments are antidepressants, and these can be used to treat depression and neuropathic (nerve) pain in MS. There are many types of antidepressants, some of which can reduce your libido and delay orgasm.

Muscle relaxants are commonly used to decrease spasms and spasticity in MS, reaching orgasm requires muscular contractions to take place so if you're taking a muscle relaxant this can affect your ability to reach a pleasurable orgasm.

You may be taking other medication on the list for an unrelated health condition.

If you're concerned any medication you've been prescribed is impacting on your sex life, it's worth discussing it with your GP, MS nurse or neurologist to explore other options. It may not always be possible to change your medication, but there may be other options, or a health professional may be able to suggest alternative strategies such as altering the time you take medication, reducing or increasing your current dose to see if that helps, or if there are non-drug approaches you can try.

3. Self-esteem

We're constantly bombarded by images on social media, TV and in magazines of the 'perfect body'. These images are impossible to live up to but can still leave you despairing of your own shape and size. Luckily there is a backlash against these images of perfection.

You can find lots of information on social media and online that promote either body positivity – having a positive view of your body and loving it for what it is, or body neutrality – where you may not love your body but are accepting of it and appreciate what it can do, rather than how it looks.

Body positivity encourages you to focus on the things you like about your body, so you might think "Although I don't have a flat stomach, I love my long legs." Whereas with body neutrality you might think "My body is amazing, it enables me to swim twice a week." Body neutrality can be a good approach if you struggle to love your body, or if it doesn't feel genuine to be positive at a particular time.

Everyone experiences times where they find it difficult to accept themselves as they are and worry about how others view them. Having a long-term condition can add to your doubts about your image of yourself generally and as a sexual person. You might feel less confident in yourself and your body. Perhaps you've had to give up activities that were closely linked to your self-image or have undergone physical changes that affect how you view yourself – you may even feel that your body has 'let you down'. It can be easy to 'medicalise' your body, especially if you're seeing a variety of different health professionals for various issues or undergoing lots of tests. Maybe you worry you'll be less attractive to your partner(s) or potential partners. If you feel like this, it's important to challenge your own perceptions.

Sadly, some people still presume that anyone living with a long-term condition and/or disability will be disinterested in, or even incapable of, having sex or being intimate. This could not be further from the truth for most people living with MS. However, being desexualised by society has the potential to affect your self-esteem. So, it's important

to challenge any negative perceptions you encounter – you have the same rights as anyone else to thrive in your relationships and enjoy an active sex life.

A positive outlook

Consider how you might replace any negative thoughts you have with more positive beliefs. It's not going to happen overnight, but it is possible to change negative patterns of thinking and replace them with a more optimistic outlook. The following are some ideas that might help.

List your strengths. It can be helpful to remind yourself of your core strengths and the things you do love about yourself – they won't have changed. Start off by listing five things that you like about yourself, then you could ask family and friends to add to your list – you might be surprised with what they come up with! Keep your list, so you can refer to it when you need a confidence boost. It can be useful to start each day with a positive statement about yourself.

Keep in touch. Try to keep in regular contact with friends and family – either face-to-face, over the phone or through social networks. This has been particularly difficult over the last few years, but catching up with what is happening with everyone can boost your mood. If you find it difficult to get out, invite a friend round for a coffee or glass of wine, or arrange a catch-up over Zoom or FaceTime, to help you feel more connected to the outside world.

Learn a new skill. If you have room in your day, learning a new skill can be a great way to boost your self-esteem and give you a sense of achievement. It can also be a way to get out of the house on a regular basis, have a bit of time to yourself or meet new people. If getting out isn't easy for you, perhaps due to childcare or other caring responsibilities, or mobility issues, there are plenty of online or correspondence courses to choose from. Some courses are subsidised, or free, if you receive certain benefits.

Volunteer. Helping others through volunteering can help you feel more positive about yourself. Maybe you have skills that would benefit others, or that you could pass on. Or you might have time to devote

yourself to a good cause. You could contact a local charity to see if there is anything you can do to support them or check online for projects in your area.

Stay active. Exercising regularly makes you feel good. It boosts your mood, increases your energy levels and your self-esteem, as well as the social benefits it can bring to your life. It can also help you reach or maintain a healthy weight and improve your muscle tone. It could have other benefits such as increasing your flexibility – which might come in handy when you're exploring those new sexual positions!

"I am quietly working on getting my confidence back following a relapse. I'm getting fit again by going out power walking with my 13-month-old baby. I'm beginning to lose weight, feel fitter and my confidence is coming back."

There's lots of useful information on the MS Trust website about exercise – how to get started if you're new to exercise, exercises you can do if you have limited mobility, tips for staying active and exercise videos.

Accentuate the positive. It can help to focus on the things that are going well in your life and that you get enjoyment from. Although your life may have changed, it is not over. Know your limitations but equally don't aim too low. You may be surprised at how many activities you've enjoyed in the past are still open to you. Laughter is a great tonic if you're feeling a bit down – maybe keep a stock of comedy films or stand-up shows for when you need a bit of a mood boost. Some people find positive self-talk or using gratitude meditation helpful.

Seek help. If you're feeling very low and your mood doesn't improve after several weeks, or life is becoming a real struggle, don't suffer in silence. Talk to someone, whether that's a friend, family member, your GP, MS specialist nurse or neurologist. Ongoing sadness or tearfulness, problems speaking, changes to your appetite and losing your enjoyment of life can be signs of depression and there are treatments that can help – whether that be talking therapies such as cognitive behavioural therapy (CBT), medication or a combination of both. Other professionals that can help include neuropsychologists, sex therapists and counsellors.

Physical confidence

Everyone experiences changes to their body during their lifetime, whether this is due to weight gain or loss, ageing, childbirth, or illness. Learning to be comfortable with your body, making the most of your best features and staying as fit and healthy as you can is key whether you find your body image changes because of your MS or for other reasons.

You don't need to be perfect to be sexually attractive – let's face it everyone's tastes are different and thankfully we don't all go for the same type! Even celebrities aren't perfect once you take away their team of stylists, make-up artists and the airbrushing. Make the most of the things you do love about yourself – maybe that's flawless skin, sensuous lips, or lush, glossy hair – and try to learn to accept the bits you're not so keen on.

There are plenty of simple things you can do to help boost your self-confidence.

- If you've always taken care of your appearance, keep it up! There's no reason to stop spending time or money on yourself if you're able to.
- Enjoy a bit of pampering. You could do this at home yourself, find a beauty therapist who can come to your home or visit a salon. Something as simple as an eyebrow shape, or a manicure can make a difference to how you feel about yourself. Whilst a facial or massage can be relaxing if you enjoy touch.
- Fragrance can have a positive impact on your mood and some fragrances can invoke positive memories, maybe of a holiday, previous sexual encounter, or other happy occasion – perhaps treat yourself to a new perfume or bath oil or rediscover an old favourite.

- Think about changing your look – this might be your hair, make-up, or wardrobe. Your hairdresser can advise you on styles that will work with your hair type and face shape. Many stores offer free makeovers at their beauty counters and some brands have 'try it on' features in their online stores. If you need guidance in the clothes department, consider enlisting the help of a fashion-loving friend or personal shopper. Some stores charge a small fee for these services, but this is often refundable against anything you purchase.

These might seem relatively simple steps, but they can make a difference. Changing negative thoughts you have about yourself won't happen overnight and a simple coat of nail polish is never going to solve all your hang-ups. But, if you can slowly learn to be more confident about your body, and embrace its imperfections, it can provide a huge boost to your self-esteem.

4. Intimate relationships

Sharing your experience of living with MS can bring a new closeness and depth to relationships. In this section we look at the importance of good communication and the value of maintaining intimacy.

Communicating with partners

We all experience pressures or tension within our relationships which can impact on our sex life at times, and this is no different for people living with MS. However, MS can bring additional psychological and/or physical issues which have the potential to create extra strains. If this is the case, good communication with your partner(s) is vital. This can be easier said than done. It may be difficult to discuss your sex life without it becoming an emotionally charged situation. Here we offer some potential ways to discuss sexual issues in a positive and constructive way.

Don't put it off. The longer you leave it the more difficult it is. For example, if you're struggling with a lack of desire, it can be tempting to avoid any intimacy that might lead to sex. This can be confusing for a partner who could feel hurt, rejected, resentful or that they've failed you in some way. Being honest means you can tackle the situation together and try and find a way forward.

Plan ahead. It's a good idea to agree a convenient time and place to chat where you won't be disturbed, rather than bringing the subject up out of the blue. Even then consider both your partner's and your own mood and use your judgement – if it feels right to talk, go for it, if not reschedule. You could use this book or other material to help you initiate the discussion.

Think about what you want to say ahead of time. If it helps, prepare notes, a script or rehearse what you want to say. If you find it hard to put things into words perhaps think about using pictures or illustrations. If you haven't already, this might be a good time to think about sharing your body map if you've carried out the exercise on your own. Feeling prepared can help bolster your confidence and help you remember the points you want to get across.

If you find it difficult to talk to your partner, write down how you feel and ask your partner to read it. Then agree to discuss the matters you've raised.

Take the initiative. If it's a partner who seems to have lost interest in sex, try to find a good time to raise the matter in a calm, non-threatening way. You might be surprised at their reasons for avoiding sex. If you're recently diagnosed, they may need some time to adjust to the diagnosis themselves. Or they may be worried about hurting you if you have sex, or even think continuing to have sex may be harmful for you. An honest discussion can help dispel any misunderstandings.

Don't get things out of proportion. It can be easy to lose your sense of perspective and imagine your problems are bigger than they are. You may find when you talk your partner has a different view and that things are less of an issue than you thought.

Be honest. It's natural not to want to worry a partner, but putting on a brave face can leave you feeling isolated and risks making them feel rejected or helpless. Being honest gives them the chance to understand what you're going through. If you're going through a particularly bad patch, it could be useful to talk to your GP, MS nurse or other relevant professional.

Be sensitive. If you're enjoying sex less, tell your partner and why you think this is – this can reassure them that it's not due to any changes in your feelings for them or their lack of prowess. Try to use phrases such as *"I feel…"* or *"I would like…"* instead of things like *"You don't…"* when discussing your issues. That way you don't sound like you're criticising or blaming them and you're both more likely to stay calm and listen to each other. If things do become a bit heated, agree to stop and talk again at another time.

Keep your sense of humour. Remember that sex is meant to be fun. A good sense of humour and laughing together can work wonders when you're talking about problems and can help to bring you closer.

Make time for your partner. It's not always easy to find time for each other, this could be due to work or family commitments, or a multitude of other reasons. As with other illnesses, MS has the potential to dominate a relationship. It can sometimes feel like it's all you think and talk about, which may make your partner feel excluded or that their needs have been forgotten. It's important to make time for each other, perhaps set aside a regular date night or both draw up a wish list of ten things you'd like the other to do for you – sexually and/or romantically. Then you can take turns in swapping treats from the list.

Be realistic. Whilst some relationships become stronger after a diagnosis of MS, unfortunately some do fall apart. If there were already problems in your relationship, they won't necessarily disappear. Your partner may not be the right person to provide you with the emotional and/or physical support you need, and you may have to consider whether your relationship can survive if this is the case. Professional counselling can help you find the best way forward (see Section 8).

Rediscovering intimacy

Intimacy is more than just having sex. Holding hands, cuddling, stroking, and kissing are important elements of any relationship – even more so if full-blown sexual intimacy is not possible. Confiding in each other, spending time together and simply being there for each other are vitally important too.

"We now have a less physical, more gentle intimacy, more cuddles. We know we're there for each other."

Maintaining intimacy isn't always easy. Here are some ideas you may find helpful.

- Intimacy doesn't just happen; it needs to be worked at. Take time out to talk to each other about how you're feeling, rather than just discussing day-to-day mundane tasks, or focusing on MS.
- If you've stopped having sex – whether it's a temporary dry spell or longer-term – a kiss, hug, gentle caress, few kind words, or love note show you still care.

"When it is too painful for sex, I try to caress, touch, hold and kiss more to remind my partner I still need and want him."

- Be patient and take things slowly, especially if you're resuming sexual contact when it's been a while. Restoring intimacy needs to come before sex. If something doesn't work, be prepared to try something different – things might not be the same as before or may not be perfect straight away. Keep talking to one another.
- Any change that needs to occur within your sexual relationship requires time and effort from you both. Be aware some sexual advances may be rejected – neither of you should take this as a personal affront, it may simply be that one, or both, of you need more time to adjust to the changes.
- Share what you do and don't like with each other. Be prepared to try new things or explore alternative sexual positions – be creative in finding ways to give and receive pleasure. For some fun ideas, see Section 8.

"We talk a lot more about what each of us likes and dislikes. This has helped bring us closer together."

- Don't be misled by popular myths about sex – there is no normal! You're not unusual if you're not having regular orgasms or full-blown sex. Talking, cuddling, caressing and massage can still give you both sexual pleasure and help maintain intimacy.
- Consider talking to your MS nurse or another health professional if you're finding it difficult to resolve your problems (see Section 6). Chances are they'll have talked to others with similar issues but if they can't help you themselves, they should be able to refer you to someone with more experience.
- You may feel you need more specialist counselling from a professional. This might be with a sex therapist who can help you explore your feelings, and your partner's if they're happy to attend with you, in a respectful, non-judgmental way.

"I tend to use my mouth now rather than my hands as I don't have much feeling in my fingers."

5. Starting new relationships

Many single people worry that they'll never find love. If you're not currently in a relationship, you might be concerned that having MS will further complicate finding a partner. Rest assured, many single people with MS do go on to have successful relationships.

You might be unsure about how to go about meeting someone new, especially if you've had to give up work and/or cut back on your social life. The pandemic had a huge impact on everyone's social circles, but even more so for those who had to shield or isolate due to MS.

If you're feeling low in confidence, it's not unusual to feel a bit unsure about flirting or embarking on a new liaison. Many people also worry about the right time to mention MS. Below we suggest some ways of meeting potential partners and how to talk to them about MS.

Widen your horizons. Look to meet new people and make friends in a social environment rather than specifically going out to try and find someone to have a sexual encounter with, or for a long-term partner. Friendships can often develop into something more. Some options are joining an exercise class, music group or enrolling on a course at college, whatever fits your interests and life. Often there are local groups for single people that organise a variety of social occasions, so this is another possibility to explore.

Consider online dating. It's now very mainstream for people to use online dating services or apps to help find a new partner. Some are quite broad-based in terms of users' backgrounds and the type of relationship they're looking for. Others are more specific, and focus on their users' interests, profession, location, or the type of relationship they're interested in – whether they're after a casual hook-up or looking for something more serious.

There are also some services aimed specifically at people with disabilities – do be aware though that this does run the risk of attracting someone who has a particular fetish or finds disability a sexual turn-on, which might not be quite what you had in mind.

Safety is a really important issue – not everyone is honest or trustworthy. Most dating services provide the ability to exchange messages via the site, so you don't have to disclose any personal information such as your email address or arrange a meeting until you're ready to.

"As a gay disabled woman, I've found it hard to develop new relationships. Instead, I've been finding it easier to meet women on the internet. It's been a good way of forming relationships and I've been travelling all over the country meeting other women because of it."

"I'm always a bit cautious and take time to get to know someone through the website, then by exchanging emails, before arranging to meet."

Social media forums. Some people prefer the idea of using social media forums on the internet. You can use them to develop friendships, but if you want more than this there are forums specifically geared up to enable sexual encounters. If you're looking for a one-off encounter, or a short-term fling rather than something that might become more serious, there are sites that specifically cater for this. Again, there are specific disability-related sites which you might feel are more appropriate for you. Bear in mind the same cautions as mentioned for online dating.

To tell or not

When you do meet someone, if they're not already aware you have MS, it introduces the dilemma of "if, what and when" to tell them. There's no right or wrong way to do this. Ultimately it all comes down to what feels right for you. You might prefer to be open from the start, or maybe you'd rather wait until you know someone a bit better and feel more relaxed with them. It may differ depending on the person and how comfortable you feel with them.

"I wait until the second date before I tell. If I like someone enough to see them again, I reckon I should tell them. If I leave it longer it feels like the elephant in the room. Somehow that seems to make it a bigger deal than it is for me; MS is just a small part of my life."

There's no way of predicting how someone will react. Most people will be surprised. Some will take it in their stride, whilst others may need a bit longer to absorb the information. But ultimately most partners adapt, especially as the relationship develops over time.

We can never be 100% sure whether any relationship is going to go the distance, there are always highs and lows, and there can be many reasons why they break down. Unfortunately, disclosing you have MS can affect the way some potential partners behave towards you, and they may choose not to continue the relationship for this reason. Perhaps if they can't deal with MS, it's better to know early on, so you can move on in your search for love and intimacy before you invest too much time, energy, and emotion.

Often how someone responds depends on how much they know about MS. If they're willing to learn more, the MS Trust has lots of information you can share with them.

6. Talking to health professionals

It's been shown that talking to a health professional about issues around sex can be beneficial and even make a difference to how you feel about yourself.

Many health professionals are used to talking about sex on a regular basis, so there's no need to feel uncomfortable or embarrassed about sharing intimate details with them. They've probably heard it all before. The important thing is to choose the health professional involved in your care that you feel most comfortable with.

Health professionals who are more used to discussing sexual health issues include:

- MS nurses
- district or practice nurses
- continence advisors
- physiotherapists
- occupational therapists
- GPs
- sex therapists or counsellors
- neuropsychologists
- urologists
- neurologists.

"Talking to someone you aren't so close to can actually be a good thing – after all, they're not emotionally linked to you and what you say won't upset or worry them on a personal level."

If you do decide to approach your MS nurse or other health professional, before your appointment have a think about what you want to say and the words you're comfortable with using. You might prefer terms such as 'private parts', 'down below' or 'nether regions',

or to make sure there's no misunderstandings you might prefer to use more biological terms such as clitoris, vagina, and labia. Using words you're more at ease with can help you relax. Another option is to use pictures or diagrams to help you explain.

"Although some members of the health profession have helped me a lot to deal with intimacy issues, no one has ever raised the issue of sexual dysfunction with me. I realise that discussing issues like this can be embarrassing, and people might prefer to deal with them in private, but I do think we need to know that it is ok to discuss such issues if we want to."

It can also be useful to think about ways to start the conversation. Although health professionals routinely ask about symptoms such as pain, fatigue, or spasticity, they may not always ask if you're having issues with sex and intimacy. It might be they're worried they'll embarrass you or you'll think they're being intrusive. They might feel they don't have time, aren't comfortable talking about sex themselves, or don't feel skilled or informed enough to talk about it, so they don't ask. This could be a missed opportunity to provide you with some welcome support or advice, so it's important that you take the lead and raise it yourself if they don't. Here are some opening lines you could try if they don't bring it up.

- *"I'd like to talk to you about some issues I'm having with my sex life if that's ok."*
- *"I'm finding that my MS is getting in the way of intimacy, is that something I can talk to you about?"*
- *"I'm having problems with my sexual relationships. Could it be my MS?"*

You could also use this book to raise the subject with them, or perhaps take a list of things you would like to discuss with them and include sex on your list.

As the conversation develops it can be helpful to share things like:

- how long you've had concerns and how it's affecting you and your relationship(s)
- the sex of your partner(s) – that way no assumptions are made about your sexual identity
- the age of your partner(s)
- if you have more than one partner whether you experience difficulties with all of them or just certain ones, or if you've had the same or different issues with previous partners
- whether your partner is also having problems
- the type of sex you're having – oral, vaginal and/or anal.

If you find that the health professional that you've approached isn't comfortable with talking about sex, or they're not giving you adequate support, ask them to refer you to somebody with more experience. Specialist sexual health clinics are available within the NHS, although access may be limited, and some areas are better served than others. If you're referred to a sex therapist or counsellor, they may be able to prescribe drugs or treatments that aren't routinely available.

Remember that any sexual problems you may be experiencing may not be due to MS. They may be caused by other health-related conditions or be rooted in psychological issues. It's important to consider and explore other possible causes when talking with health professionals.

7. My partner has MS

This section is for you if you're in a relationship with someone who has MS. It aims to give you a better understanding of how MS could possibly affect intimacy and your sex life. It offers tips to help you and your partner talk about this sensitive subject so you can work through any concerns that arise together.

Some of you will have been with your partner before their diagnosis, whilst for others MS will have always been present in your relationship. MS can affect many aspects of life. It may be that since the diagnosis, or because new symptoms have developed, your lives have had to change to some extent. For many of you those changes may be minimal, but for others they may be more extensive.

Certain aspects of your relationship may also have been affected. It's not always easy to know how best to support your partner – perhaps you don't know what to say or how to comfort them. Equally you may be experiencing a whole range of feelings that are affecting you physically and/or emotionally too.

You may take any changes in your stride, but it's not unusual to feel anxious about what the future might hold. You may be sad that the life that you have together might be different to the one you had imagined. You may feel guilty if you're struggling to feel the same way about your partner. These feelings are entirely normal, you won't be the first – or the last – person to feel this way.

"I think partners should know that it's natural for them to grieve the changes that MS may have forced on them. If you do feel bitter or resentful, it's better to acknowledge those feelings rather than bottle them up."

Unfortunately, there aren't any easy answers, but the fact you're reading this shows you care and want the best for you, your partner, and your life together.

What can I do to help?

Just being there is of huge benefit to your partner. In general, it's best to take your cue from them. MS is a variable condition and symptoms can come and go. They may feel much more positive on some days, whilst on others they may need more support. Most people with MS want to be treated as themselves, not as a person with MS or a patient.

You're never going to always have the perfect response for your partner, but simply listening to their concerns is reassuring. There may be times when you feel overwhelmed yourself and need some time out. Suggesting taking a break and picking up where you've left off later can give you space to think about your own feelings. If you've given your partner the space to talk freely, hopefully that means that they'll be open to listening if, and when, you need to talk.

Learning more about MS can give you a better understanding of what your partner is going through. Many of the symptoms, such as pain and fatigue, are invisible – because they can't always be seen – so they aren't necessarily obvious to other people. But this doesn't make them any less real or difficult to cope with. If your partner is complaining they feel exhausted, they're genuinely not making excuses.

It's vital you look after yourself too. Although your partner is the one with MS, your own health and emotional wellbeing are important. If your needs are being met and you're feeling your best, you'll be better placed to support your partner. The following simple steps can help:

- get plenty of sleep
- eat healthily
- drink plenty of water regularly throughout the day
- make time for yourself to relax or socialise
- exercise regularly – even a brisk 20-minute walk can be beneficial if you have limited time.

How might MS impact on our relationship?

Lots of things can affect the balance of a relationship – family or work commitments, illness, jealousy, financial problems, or a lack of communication. Living with MS may mean your partner feels less self-confident or less positive in their outlook, especially if it has brought significant changes or any loss of independence, such as not being able to work as many hours or being less mobile than before.

Your partner may also find it difficult to believe that they're still sexually attractive to you. They might feel they're increasingly a burden – especially if the relationship is moving from one of equal partners to that of carer and cared for.

These changes can have a profound effect on the way you view each other sexually. If your partner is unwilling to have sex, it can be difficult not to feel frustrated, unfulfilled, rejected, or unloved. It's unlikely that this withdrawal from shared intimacy reflects any change in their feelings for you. Rather, the physical and emotional effects of MS can impact on their sexual response – the consequences of this may only be temporary, but they can be longer-term.

Section 2 of this book explains some of the reasons why your partner may not be as willing to initiate sex or respond to your advances.

If sex is currently off the table, rather than focusing on trying to solve any sexual issues, try to show affection and take pleasure in any shared intimacy and sensual moments you do still enjoy together. This will help you maintain closeness.

"I know she feels she can't fully fulfil her part in this relationship. She has very low periods where her self-image/confidence is at breaking point. She gets very jealous of my abilities as an able-bodied woman. I try to encourage her to attempt to try things to build up her self-confidence."

Working through any difficulties together can bring you closer and strengthen your relationship. Talking about any physical or emotional issues, both yours and theirs, can reduce the risk of any resentment building up. However, in some cases you might find you need some relationship or sex counselling to move forwards – see Section 8 for some sources of help.

There's no way of predicting if, and exactly how, a relationship will be affected by MS. Some people find that it can put their relationship under pressure at times, but after a period of adjustment, they often come out of it feeling closer than ever.

"I think our relationship is stronger now. We have a much gentler intimacy. We talk a lot and spend time just simply kissing and cuddling. If anything, it has brought us closer."

8. Resources

Games to play

Don't take these too seriously; the idea is to have fun and improvise!

Sit on a chair and ask your partner to stand behind you.

- Ask them to run their hands through your hair and massage your scalp using the tips of their fingers, gently covering your whole head.
- Ask them to move around and sit astride on your lap facing you.
- Ask them to continue massaging your head, moving on down to your neck and shoulders.
- Ask them to delicately kiss your face as they do this.

Sit on a chair with your head tilted backwards.

- Ask your partner to undo your clothing to expose your neck and chest.
- Then ask them to stroke your forehead, cheekbones, and nose.
- Ask them to wet their fingers and rub your lips – lick their fingers very slightly as they are doing this.
- Ask them to stroke your chin, moving on down to your neck, shoulders, and collarbone.
- Move their hands to your chest and get them to play gently with your nipples with their moistened fingers.
- Ask them to kiss you deeply.

Sit down with your legs open as wide as you can. Ask your partner to kneel between your legs facing you.

- Tell them to place a hand on each of your knees.
- Bring their face as close as possible to yours so the tips of your noses touch.
- Move their hands slowly from your knees and up your legs until they are grasping the inside of your thighs about halfway up.
- Place your hands on your partner's shoulders and kiss them softly on the lips.
- Move your partner's hands to the top of your inner thighs and kiss them more deeply.

Sit on a chair fully clothed.

- Ask your partner to walk very slowly around the chair, breathing lightly upon your neck, ears, and face whilst they remove all your clothing – except for your pants.
- Let their hands drift over your body and ask them to give fleeting kisses on your nipples as they move around the chair.
- Ask them to part your legs and put their head between them, but not to touch you with their hands.
- Ask them to blow gently on your genital area and kiss you fleetingly over your pants.
- Ask them to play with your clitoris, labia, and vaginal entrance through the fabric of your pants with their thumb and forefinger.

Ask your partner to take off all their clothes.

- Using a soft hairbrush, brush them all over.
- Try brushing in different directions to create a variety of sensations.
- Ask your partner to return the compliment.

You could try using a stiffer brush to produce stronger sensations but beware of being too rough!

Blindfold your partner with a silk scarf and then ask them to sit or stand in front of you.

- Slowly undress them – as you remove each piece of clothing, stroke and caress that part of their body.
- Stroke their whole body with your fingers, starting with their face and gradually working down to their feet.
- Explore each part of them as you go.
- Vary the intensity of your touch. Tease them sometimes. Use your breath to blow on their skin.
- You may want to explain to them what you're going to do, or you may prefer to stay silent and keep them in suspense!
- As you explore different parts of their body, you may want to ask them how they're feeling – are they enjoying it? Does the touch feel sensual?

Next time swap roles and you wear the blindfold whilst your partner explores you. You could also try this with the person doing the undressing wearing the blindfold.

Organisations

Sexual health

FPA

Provides sexual health information and advice on contraception, sexually transmitted infections, pregnancy choices, abortion and planning a pregnancy.
fpa.org.uk

British Association for Sexual Health and HIV

Produces patient information leaflets concerning sexually transmitted infections and other sexual health problems.
bashh.org

Helplines and self-help groups

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.
ipm.org.uk

Sex and disability helpline

Offers support on relationships, sexuality, dating and sexual services. Professionally staffed helpline available weekdays 11am-5pm provided by the Outsiders Trust.
T: 07872 681982
T: 01997 421019
E: sexdis@outsiders.org.uk
outsiders.org.uk/outsidersclub/helpline/

The Outsiders Trust

A private social, peer support and dating club run by and for people with physical and social disabilities seeking to make friends, gain confidence and find partners.
T: 07900 957393
E: members@outsiders.org.uk
outsiders.org.uk

Switchboard

Offers information and support from trained volunteers to the LGBTQ+ community by phone or through instant messaging.
T: 0300 330 0630 (10am-10pm)
switchboard.lgbt

Regard

Provides information and support to LGBTQ+ people who self-identify as disabled.
regard.org.uk

Bladder and Bowel Community

Supports people who are living with conditions that affect their bladder or bowel.
E: help@bladderandbowel.org
bladderandbowel.org

National Domestic Abuse Helpline

24-hour helpline run by Refuge to support women experiencing domestic abuse. Live chat service available Monday-Friday 3pm-10pm via the website.
T: 0808 200 0247
nationaldahelpline.org.uk

Women's Aid

Provides specialist, domestic abuse support to women and children via email or live chat on their website.
E: helpline@womensaid.org.uk
womensaid.org.uk

Galop

Provides support for LGBTQ+ people who've experienced abuse and violence.
T: 0800 999 5428
galop.org.uk

Counselling

Relate

Offers advice, relationship counselling, sex therapy and support face-to-face, by phone and live chat through the website.
relate.org.uk

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.
T: 0208 106 9635
E: info@cosrt.org.uk
cosrt.org.uk

Volunteering

Do-It

Helps you find volunteering opportunities near you.
doit.life/volunteer

Volunteering matters

National charity offering volunteering opportunities for young, older, and disabled volunteers.
volunteeringmatters.org.uk

Reach volunteering

Website for volunteers with specific skills including accountancy, marketing, law, and mentoring.
reachvolunteering.org.uk

Body positivity/body neutrality

The Be Real Campaign

National movement campaigning to change attitudes to body image. Includes organisations which can support those with low body image, mental health difficulties or exercise.
berealcampaign.co.uk

Publications

My secret garden

A collection of women's sexual fantasies by Nancy Garden.

Forbidden flowers

More women's sexual fantasies by Nancy Garden.

Dare: what happens when fantasies come true

A book exploring women's fantasies and what happens when they try to enact those fantasies by Tracey Cox.

Desires reborn

Unique collection of erotic stories involving people with disabilities by Penny Pepper.

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.

The body image workbook

An eight-step programme for learning to like your looks by Thomas Cash.

The sex book

Explores sex, health, and sexuality in a straightforward, uninhibited, accessible, and adventurous way by Suzi Godson.

Enabling romance

A guide to love, sex, and relationships for people with disabilities and the people who care about them by Ken Kroll.

The ultimate guide to sex and disability

A self-help guide for people living with disabilities, chronic pain, and illness by Miriam Kaufman.

Tactile mind

A handmade book of tactile 3D nude images for the blind or visually impaired by Lisa Murphy.
tactilemindbook.com

Sex toys and aids

Ann Summers

Stocks a wide range of sex toys available through their website, stores throughout the UK or home parties. Their website includes a live chat where you can ask for advice from their product specialists.
T: 0333 440 6969 (Customer Services)
annsummers.com

Lovehoney

Offers a wide range of sex toys through their website which includes a live chat and advice guides.
T: 0333 103 6969
lovehoney.co.uk

Sh! Women's Store

Female focused sex toys uniquely designed and made by women for women. The website includes advice guides and details of events and online classes to encourage honest conversations about sexual wellbeing.
T: 0333 344 4005
sh-womenstore.com

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.
T: 01543 899317
spokz.co.uk

About the authors

Information Team, MS Trust

We are a UK charity that believes nobody should have to manage multiple sclerosis alone. We are here for everyone affected by MS, from the moment of diagnosis and throughout their journey.

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