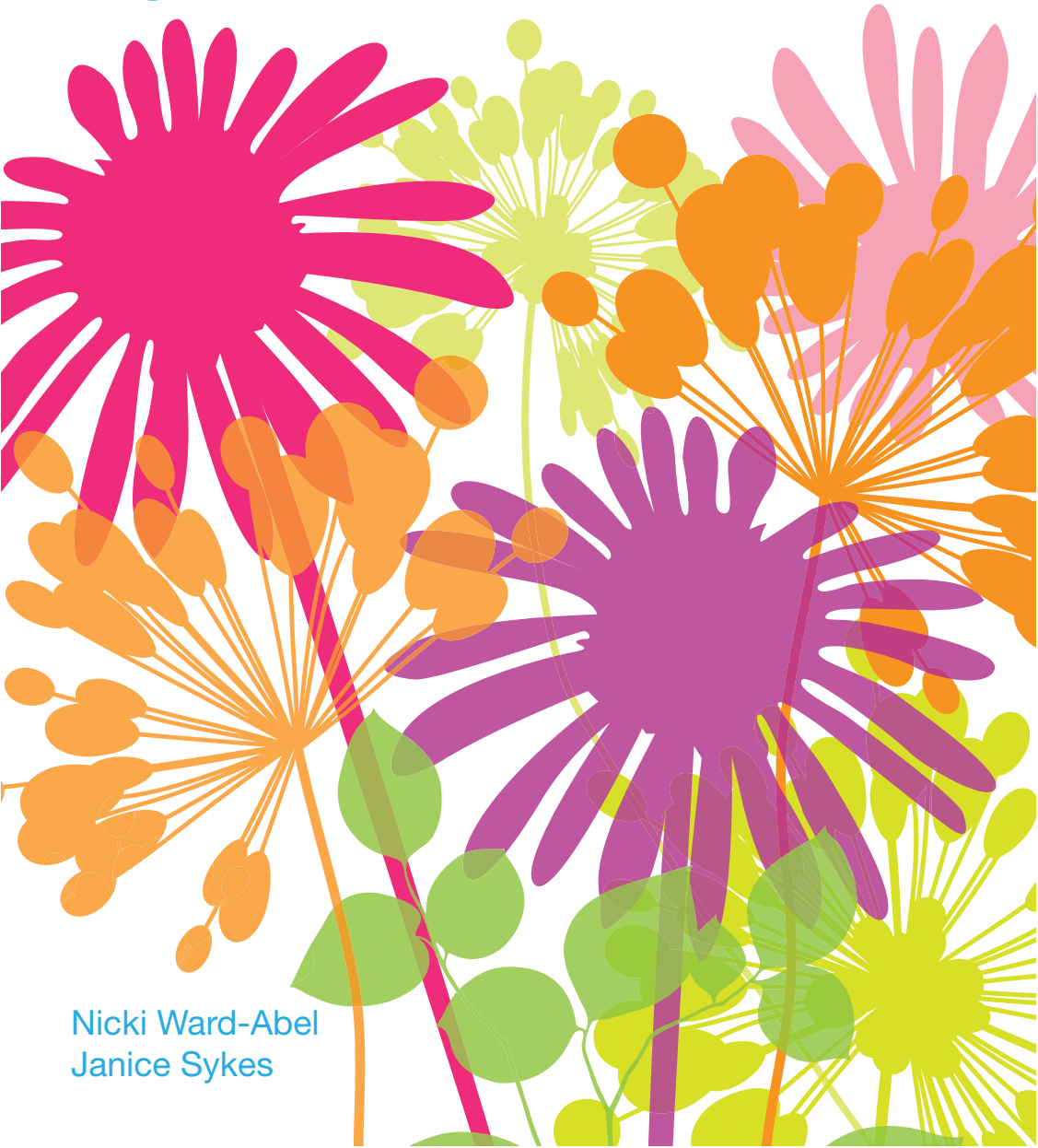


# Sexuality & MS

a guide for women



Nicki Ward-Abel  
Janice Sykes

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

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

## MS Trust information service

### Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter Open Door, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for Open Door and much more visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)

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

**email** [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

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Letchworth Garden City  
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## Introduction

This book has been produced for women who have MS and are finding it hard to enjoy fulfilling sexual activity.

*“All the books on MS only seem to offer men any help with sexuality.”*

Judith

This book is relevant for women with MS – those who are single, those in long standing or new relationships, gay or bisexual. If you are experiencing sexual problems and are in a relationship, partners can also be affected, so we have included a section for them to read. This may help them understand what you are experiencing or feeling and help you share the problems and work together toward finding solutions.

*“MS requires us to overcome barriers and to discuss issues which are intensely personal and which before our illness we would have been able to keep private had we wished. Issues like incontinence and lack of mobility, for example, things which are hard to discuss and painful to admit to. I would urge everyone to be more open to solutions and to discussion than they might have been before their diagnosis.”*

Esther

This guide explains how MS can impact on a woman's sexual response and offers some practical solutions for coping with symptoms that can interfere with sexual activity. Not all women with MS will find that their sex life is affected. Not all sexual problems are related to MS.



## Introduction

*"I can find that when I am having a relapse, I lose the sensation in my genital area. This is quite weird and I always wonder if the sensation will return, but as the relapse settles I find that the feelings come back too."*

Mary

*"If sex is painful, tiring or just not what you need sometimes, then the solution is to be able to say so. No one should feel under pressure to 'deliver' as it were!"*

Esther

MS is a very individual and variable condition; no two people experience the same symptoms in the same way so not all of the information contained in this book will be relevant to you. You can pick and choose the sections that are most applicable to your situation.

Many of us find it really hard to talk about sexual matters and this book suggests ways to raise the subject. This might be with friends, partners or health professionals involved in your care.

Throughout the book, we include quotes from women who share their experiences of living with MS and offer tips for minimising its impact on sexual and intimate relationships.

It is important to follow guidelines on safer sex to avoid unplanned pregnancy and to protect against the risk of sexually transmitted infection. Further information on safer sex is available from your local family planning clinic, from the FPA (Family Planning Association) [www.fpa.org.uk](http://www.fpa.org.uk) or [www.playingsafely.co.uk](http://www.playingsafely.co.uk).

Please note: The information provided in this book offers guidelines and ideas for addressing sexual problems; by no means does it cover every possible situation you may encounter.



## Section 1:

### A woman's sexual response

A woman's sexual response is influenced by many things. This may include hormonal changes such as the menstrual cycle, pregnancy or menopause; many women notice that their attitude towards sex changes at different times of the month and different stages of their life. External factors, such as who you are with, the circumstances and any distractions can all play a part in how you feel at any time.

#### Sexuality

The term 'sexuality' is difficult to define and our sexual identity is unique to each one of us.

Sexuality is concerned with how you express your sexual identity, how you feel about yourself as a woman, your femininity, your sense of self-worth and self-image. It links to the way you project yourself and communicate with others including your partner or potential partners.

Your sexuality is formed within your background, cultural or religious beliefs and is shaped by sexual experiences and individual preferences. In short, your sexuality is reflected in your individual personality and your lifestyle, and goes far beyond your ability to engage in and enjoy sexual intercourse.

#### The sexual response

The terms 'sexual functioning' or 'sexual response' relate to the physical act of engaging in sexual activity, sexual intercourse or other forms of intimate contact. This can include non-touch activities such as cyber or telephone sex.



## A woman's sexual response

Arousal generally begins in the brain following erotic stimulation from sight and thought, such as sexual images, remembering or picturing sexual situations; in fact, depending on your preferences, just about anything! Following these stimuli, the brain then processes and relays messages to the sexual organs along the nerve pathways of the spinal cord. Other parts of the body, such as the circulatory system, are also involved so there are many opportunities for things to become problematic. There are different ways of explaining the female sexual response. These are the most common concepts:

**Sexual interest/desire:** Desire (libido) can be an important factor in the female sexual response and can be affected by a number of physical and mental factors. The way you feel sexually is closely connected to your state of mind – some have described the brain as the most powerful sexual organ. A whole range of mental factors can affect sexual desire, including self-esteem, how you or your partner are feeling in terms of mood, stress levels and attitude to one another. Confidence in your physical self, trust and safety to play out fantasies or say what is exciting or pleasurable all play a part.

Although some women do not initially experience desire, they can still respond to and enjoy sexual activity.

**Sexual arousal and orgasm:** When you experience desire, blood flow increases to the genital area and particularly the clitoris. The clitoris is a sensitive area located in the female external genitalia that responds to touch by swelling with blood and increasing in size. It is the most important part of the female anatomy when it comes to sexual pleasure: over two-thirds of women in the general population cannot orgasm by vaginal penetration alone and require stimulation of the clitoris to achieve full arousal and orgasm. As the clitoris swells, so do the tissues or lips (labia) that surround the entrance to the vagina. The labia open slightly, increasing access to the vagina during intercourse. The internal structure of the vagina elongates and balloons at the top to allow for penetration.

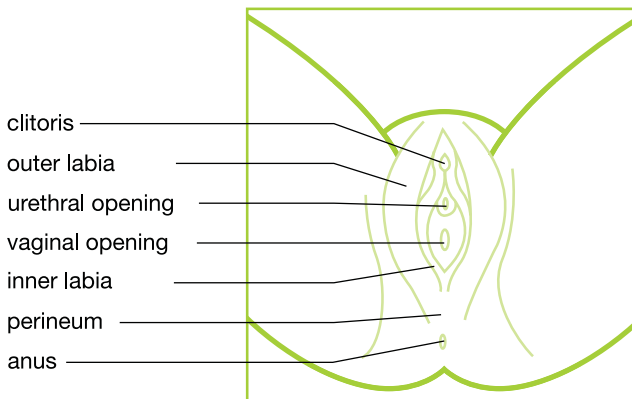


## A woman's sexual response

At the same time, the vagina produces more lubrication to make penetration easier and more comfortable. Lubrication is really important for comfortable and enjoyable sex, but the amount of lubrication present in the vagina does not necessarily coincide with a woman's degree of arousal or her desire for intercourse.

Nipples can also become erect, breasts enlarge slightly and the veins in the breast may appear more visible.

As sexual arousal builds, there is an increase in energy within the nerves and muscles in the genital area and other parts of the body, causing the muscular contractions that lead to orgasm. Many women do not reach orgasm every time they have sex and, as already stated, the majority of women cannot achieve orgasm solely through vaginal intercourse.



## Section 2:

### MS and sexual response

**Not all women with MS will experience changes to the way in which they respond sexually.**

There is no sure way to predict who will experience changes, but studies suggest up to 80% of women with MS report some problems at some point in their lives. Some may be caused by other health related issues not connected to MS.

Sexual problems may be caused directly by MS lesions in the brain and spinal cord or relate to MS symptoms that affect sexual response. Some may arise from the psychological, emotional and cultural consequences of living with MS. Problems can also occur as a side effect of prescribed medications; there are over 100 medications that can affect sexual responses.

Sexual problems can occur at any time during the course of MS and can come and go, may persist and may have been present before diagnosis.

Sexual problems may, or may not, be related to the length of time you have had MS or the physical limitations it brings. However we do know they are more common in those women who have changes in their spinal cord and experience walking and/or bladder difficulties. Nerves that control walking and bladder control are located close to those that link to the sexual organs.





# MS and sexual response

## How does MS affect sexual response?

There are three key areas of difficulty in terms of sexual response for women with MS:

- loss of libido (desire)
- vaginal dryness
- loss of sensation and difficulty achieving orgasm

Specific symptoms of MS can also affect the sexual response. These include:

- fatigue
- hypersensitivity
- pain
- spasticity
- bladder and bowel problems
- mental health

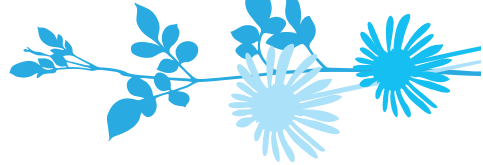
The physical process of sexual arousal begins in the nervous system (the brain and spinal cord). The brain processes and relays messages to the sexual organs via the nerve pathways in the spinal cord. Many different areas of the nervous system need to be involved to produce a sexual response.

MS lesions (areas of scarring) tend to form randomly throughout the nervous system and can damage nerve pathways that affect sexual response in a number of different ways. For example, lesions in the spinal cord can reduce sensation in the clitoris and the vagina, while lesions in the brain can affect libido.

## Sexual problems and practical solutions

### Loss of libido

Loss of desire is a problem for many women - not just those with MS. It is estimated that at any one time, several hundred thousand women in Britain are affected by low levels of desire. MS can affect your libido either directly – as a result of lesions in the brain, for example – or indirectly – for example as a result of anxiety, fatigue, loss of self-esteem or the side effects of medication.



## MS and sexual response

If your desire for sex is diminished or lost you may be reluctant to engage in sexual activity and unlikely to make the first move. However, many women who experience loss of desire are physically capable of becoming aroused and having an orgasm when they do have sex. Like many things in life, sexual activity benefits from effort and commitment even if it seems rather forced or lacking in spontaneity at first. The following suggestions can help:

**Make time for foreplay:** sex is so much more enjoyable when you are fully engaged in the activity. The more you focus on your senses, the greater the satisfaction you will experience. This will apply to partners too. Many women can be ‘slow to warm up’ and expressions of affection and foreplay are very important for creating the right mood. Allowing time for this to be enjoyed can be a rewarding aspect of sexual activity and enough in itself for some women. See Games to play in Section 6 for some fun ideas.

*“I have very little sensation in my genital area and only get aroused if my partner takes time. Sexual intercourse is more pleasurable for my husband. But I still enjoy the intimacy.”*

Ruth

*“It was worth the embarrassment of telling my partner what I really enjoyed. Now he really knows what turns me on!”*

Mary

**Set the scene:** consider what will ‘turn you on’ mentally and relax you physically. Create a warm, sensuous environment by lighting scented candles, playing soothing music and using aromatherapy oils in the bath. Try to make sure you won’t be rushed or disturbed.



## MS and sexual response

*“I allow more time and peaceful privacy to help me and my husband.”*

Maz

**Relax:** stress and tension can have a very negative impact on desire – it is easier said than done, but try to clear your mind of worries and anxieties when you are planning to have sex. Simple measures such as a warm bath or a glass of wine may be enough to help you relax but if stress is an on-going problem, it might be worth investing in a relaxation CD which can teach self-help techniques such as breathing exercises or self-hypnosis.

**Indulge your fantasies:** fantasising can be helpful for some women. First, you need to consider what exactly it is that you find stimulating. Is it imagining you are on a deserted beach having sex, is it watching erotic movies, or is it imagining yourself in a ‘dangerous’ situation such as having illicit sex or having sex with someone you would not normally have sex with? Having a fantasy is not ‘dirty’ or ‘abnormal’ - most women have their own personal fantasies. You may want to share them or you may prefer to keep them private. Some people find that certain novels or films can be sexually stimulating. You can either buy or rent these or you may find that one of your friends has something suitable that they could lend to you. See Publications in Section 6 for more suggestions.

*“We share more fantasy as we get older and more comfortable with each other. We have started to enjoy oral sex more now.”*

Ruth

**Get in touch:** touch can be very therapeutic and an effective way to restore or maintain intimacy even when full sexual activity is not possible. But for some women touch is too painful and this is considered later in this book. Massage using fragrant oils on the skin (try almond oil if you have sensitive skin) - you might want to buy a book about massage or



## MS and sexual response

borrow one from the library. Touching and stroking each other can bring you closer together and can enhance feelings of tenderness. Gently touch where there is feeling – try stroking behind the ears, massaging the hair and scalp or nibbling the neck.

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

Karen

**Explore your body:** body mapping is a simple technique that can help an individual or couple rediscover sexual pleasure. It is a way of exploring your own, or your partner’s, body and identifying exactly where you feel pleasant, decreased or altered sensations. Find a comfortable room where you will be undisturbed for 15-20 minutes. Take off your clothes, lie down and systematically touch each other’s body from head to toe (or all the places you are able to reach). You can also carry out this mapping on your own; you do not need a partner.

Really concentrate on what you feel and where you are being touched. Consider which areas give you sensual pleasure, and those that cause discomfort or sensory change and, if you are with a partner, describe what you are feeling. A leading expert recommends that you ‘map’ your entire body and not only the areas that are commonly associated with sexual pleasure. You may find you have ‘erogenous’ zones that you were previously unaware of, such as the back of your neck, your ears or your toes. It is recommended that you do not attempt to reach orgasm for at least ten body mapping sessions, as this will defeat the purpose of the exercise.

**Psychological problems:** for some women, feelings of guilt or shame may impact on sexual identity, responses and activities. Some women may not be able to identify what they are feeling and may need support in exploring their thoughts. In these instances psychotherapy or relationship counselling may be beneficial. For further information on how to access services such as these, see Section 6.



# MS and sexual response

## Vaginal dryness

Some women with MS produce less vaginal lubrication and this can make penetrative sex painful; even touch can be uncomfortable. Dryness can be caused by a number of factors, many of them unrelated to MS, including hormonal changes and certain types of medication.

Vaginal lubricants can be extremely effective at treating dryness and using them may have the additional benefit of increasing sensation in your genital area. It is recommended that you choose a water-based lubricant rather than oil-based products; oil-based products can damage condoms and do not flush out of your body as easily as water-based lubricants and this can increase the risk of an infection. They are available either as liquid or jelly preparations.

Examples of water-based lubricants are KY liquid, Sensilube and Astroglide. Lubricants can be bought from chemists or supermarkets or online.

### Top tips:

- when using lubricant, apply it liberally.
- once you have applied the lubricant, you can reinvigorate it with water or saliva.
- try out different types of lubricant to see which works best for you.

Several of the companies listed in Section 6 sell a wide range of lubricants, some of which are specially formulated to produce ‘warming’ or ‘tingling’ sensations.

## Loss of sensation and difficulty reaching orgasm

Some women with MS experience loss of sensation in their genital area and will require more intense stimulation in order to achieve orgasm.



## MS and sexual response

*“Thankfully my husband is extremely understanding but I have never told him, even to this day, that I had no sensual feeling from the waist down for 6 months following the first relapse.”*

Suzanne

There are many misconceptions surrounding orgasm and these can often cause conflict within relationships. A common expectation is that partners will also orgasm and that this will happen at the same time. In fact, this is relatively rare. It is also worth remembering that sex does not have to result in an orgasm every time; sex without an orgasm can still be stimulating, intimate and very pleasurable.

Less than one third of women in the general population achieve orgasm through penetrative sex – the majority require clitoral stimulation. Some women never experience an orgasm and cannot achieve climax despite the nature or skill of sexual activity.

The following may help women with MS:

**Use a vibrator:** nowadays people are far more open about using vibrators – they can be purchased on the high street and in some supermarkets. However, if you prefer a more discreet approach, there are plenty of reputable online suppliers that offer a wide range of products (see Section 6).

Many women find it much easier to orgasm when they use a vibrator. They can be used on the clitoris, vagina or anal area. Using a vibrator can often compensate for loss of sensation and intensify feelings that are still present. If you have always achieved orgasm through clitoral stimulation you may want to consider a vibrator that does not penetrate vaginally.

You may need to use the vibrator vigorously. A mains operated vibrator is more powerful than a battery-powered vibrator. A vibrator frequency of 80 hertz may be suitable for younger women, women aged 40+ may respond better to 120 and 150 hertz. Vibrators with variable tones and speeds are available.



## MS and sexual response

*“In order to reach orgasm, I have to use a vibrator. It was actually a partner who suggested that, and I was very embarrassed at first, but it brought an added dimension and creativity to sex! I would urge anyone having difficulty reaching orgasm to invest in a vibrator! Don’t be embarrassed about it – they sell zillions of them worldwide, so it’s not exactly being weird or subversive any more. Partners would find this very erotic and often want to take charge.”*

Suzanne

**Oral sex:** not everyone feels comfortable about oral sex, but if you have not explored this before, why not start with kissing in the genital area to see how it feels. More women can achieve orgasm through oral rather than penetrative sex.

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

**Explore pleasure:** every woman needs to be aware of exactly what gives her sexual pleasure and this is particularly important if you have altered sensation in your genital area. If you do not know what turns you on, then it is doubly difficult for partners! Masturbation is an excellent means of self-discovery. It can allow you to establish exactly what gives you the most pleasure and enjoyment. You can either use your fingers (it’s a good idea to use some lubricant if you can) or a vibrator. If you have not done this before, you may feel shy, guilty or embarrassed at first so make sure you are not going to be disturbed. Start by exploring your nipples before you move on to your genital area. Find out where you like to be touched most and what intensity of touch gives you the greatest pleasure. Vary the pressure and rhythm of your touch. You might like to try using a variety of textures, such as a piece of silk, a furry fabric or rough gloves. Once you have worked out what works best for you, you can have fun relaying this information to a partner!



## MS and sexual response

You may want to consider experimenting with a finger vibrator when exploring your genital area. These are worn on your finger like a ring or thimble and are aimed at intensifying sexual stimulation. They can be obtained from chemists, supermarkets or through the internet (see Section 6).

Body mapping (see Loss of libido in Section 2) can be an excellent way of finding alternatives to penetrative sex.

### General tips for achieving orgasm:

- hormonal changes can affect your ability to orgasm: experiment to discover your most orgasmic time of the month.
- try panting for a short while when having sex (not too long as this can make you light headed!).
- exercise pelvic floor muscles to improve decreased vaginal tone – this may enhance orgasmic response.
- raise your pelvis during sex by placing a pillow under your hips – some websites sell specially designed pillows or wedges (see Section 6).
- hang your head over the end of the bed when having sex.
- lie across the bed with your legs hanging over the bed, this allows easier access.

*“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.”*

Mary

If the suggestions outlined above fail to help, you can obtain lots of other help and practical tips from sexual or relationship counselling. Do not regard this as a failure - it is a positive management strategy that can be really helpful for many couples.



## MS and sexual response

### Is there a female equivalent to Viagra?

Research has examined the effect of Viagra and similar drugs on women with MS who have sexual difficulties and it has been found that they do not help. This can probably be explained by the fact that these drugs help achieve an erection but they are not an aphrodisiac – they do not influence a woman’s desire, arousal or orgasm. However, research is ongoing to investigate medication as a means of helping minimise a woman’s sexual difficulties.

If you are referred to a sex therapist or counsellor they may be able to prescribe treatments or other ways of managing problems that are not routinely available (see Section 5).

### Fatigue

Fatigue is one of the most common symptoms of MS and can be the most disabling. Often when you are tired, the last thing you want to do is have sexual intercourse and as a result, you may even shy away from any form of intimacy in case it leads to sex.

If fatigue is a particular problem for you, the following advice may help.

- establish the time of day when you are likely to have most energy (often in the morning).
- experiment with different sexual positions to see if you can find any that require less of your energy. One option to try is ‘spooning’ when the couple lie side by side with penetration from behind.
- if you are particularly tired, use foreplay or oral sex to achieve orgasm.
- it can be helpful to take a rest before sexual activity and some women like to take a cool, invigorating shower.
- use the ‘stop and start’ technique: this involves taking a break from sexual activity when you become tired, then starting again when your



## MS and sexual response

energy returns. This break may only last for a few minutes but can allow you to recover and can ‘tease’ your partner and actually add to the sexual excitement.

- remember that a ‘quickie’ can be great fun and still be sexually satisfying!

*“On nights when I know I am going to be spending time with my partner, I try to plan my days around this – logistical nightmare sometimes.”*

Karen

For further information, read the MS Trust booklet *Living with Fatigue* (see Section 6).

### Hypersensitivity (dysaesthesia)

While lack of sensation can be a problem for some women with MS, others are affected by hypersensitivity. This can be an uncomfortable, abnormal sensation, such as pins and needles, burning or crawling feelings, numbness or tightness for which there is no external cause. Some women find that their skin can become so sensitive that even the gentlest touch can be unpleasant. There are a number of medications that might help so talk to your specialist about this.

*“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 and to get him used to the idea that what I enjoy sexually changes from day to day.”*

Esther



## MS and sexual response

The body mapping technique (see Loss of libido in Section 2) can be a good way of discovering areas of the body where you do like to be touched. Explain to your partner what you are experiencing and together you can discover what will work best for you. However, if being touched causes you pain, then body mapping may be too uncomfortable for you. You may have to experiment with this technique to see if it can be of any benefit to you.

*“Super sensitivity can be a major problem. Small delicate touches can cause pain, which makes you recoil. Trying to put this over to the other person is very difficult. ‘It’s not you as a person – it’s me – but I do still like you – honest!’”*

Michelle

*“Simply changing positions during sex to avoid areas which are sensitive coming into contact with sheets/skin can help.”*

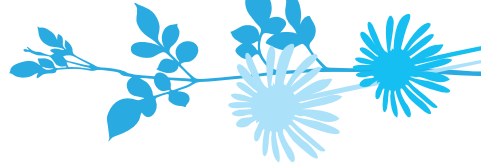
Esther

For some, hypersensitivity means that penetrative sex or sexual touch is not an option. Some women find that the following alternatives can provide sexual pleasure:

- talking sexy or phone sex
- watching erotic films
- reading erotic stories

### Spasticity

If you are prone to spasticity it can be difficult to find a sexual position that is comfortable. Because of the nature of spasticity, the legs are inclined to clamp together with the minimum of stimulus, which can certainly make sex something of a challenge!



## MS and sexual response

*“Getting turned on sends me into full body extension, which is an embarrassing reaction to a snog. Having sex is complicated because of my adductor spasms and weakness.”*

Jan

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

Jan

Below are some tips for minimising the effects of spasticity:

- the right position is key. Spastic movements are often triggered by lying flat on your back with your legs stretched out, so try to avoid this position whenever possible.
- experiment with different positions to allow you to achieve penetration. Try standing whilst leaning against furniture, lying on your side or on top of your partner. You will need to find a position that is most comfortable for you and also identify movements that trigger spasms or other unwanted movement of your body so that they can be avoided.
- try using pillows under your knees or your bottom. This can reduce spasm and may help achieve deeper penetration. If you are lying on your back, you can sometimes reduce the risk of spasms by putting a rolled up towel in the small of your back. Specially designed cushions and wedges can be purchased which may help you find the best position (see Section 6).
- ask your GP or MS specialist nurse whether you can increase your anti-spastic medication prior to sexual activity.
- using massage and relaxation techniques prior to intercourse can help relax the spastic movement.



## MS and sexual response

- try exercising your limbs gently prior to having sex. If this is difficult for you, ask your partner to help. You may want to speak to your physiotherapist or MS specialist nurse about 'passive movements'.
- relax and trust your partner; this is essential and can be a major factor in terms of minimising spasms.

*"Having a couple of glasses of red wine can help calm the twitchiness and spasms, and help relax you too."*

Karen

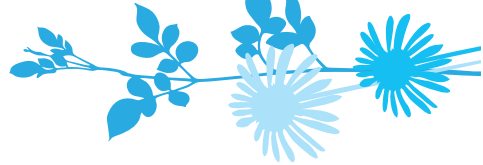
## Bladder and bowel problems

Bladder and bowel disturbances can understandably cause great anxiety and can prevent some women from wanting to be sexually intimate. Many women fear they will lose control and be incontinent when they are having sex, they feel that it is not worth taking this risk as the embarrassment would be too great.

It may be helpful to know that lots of women in the general population leak urine when they orgasm - some partners even find it a turn on. It is important to discuss your worries with your partner – talking about your fears is often very therapeutic and can clear up misunderstandings.

*"I have had two episodes of losing control of my bowels, and the second incident occurred on holiday with my partner. I am now glad that I had no chance to hide what had happened. It made us both sad and worried, but it reassured me that for my partner, such symptoms are not tied up with the way he feels towards me either emotionally or sexually."*

Esther



## MS and sexual response

Below are some practical strategies for bladder and bowel problems:

- seek the advice of a continence specialist, who is trained in the management of bladder and bowel problems. They can carry out an assessment and may then be able to suggest helpful management strategies. Your GP or MS specialist nurse can refer you or you may be able to contact the continence advisor directly.
- consider whether you are experiencing repeated urine infections, which can cause incontinence. These are common in women with MS and can be aggravated by sexual activity.
- pass urine just prior to having sex, and also just after to minimise the risk of bladder infections.
- try limiting your fluid intake for a few hours prior to sexual activity, although this is not something you should do on a regular basis. This can reduce the amount of urine produced by your kidneys.
- place protection such as towels on the bed. This doesn't remove the problem of incontinence but may help you relax a little. Perhaps a racy red towel might make the situation sexier!
- self-catheterisation prior to sexual contact can be helpful. If your partner is willing, it can even be incorporated into foreplay.
- if you use an indwelling catheter, experiment with alternative sexual positions such as 'side spooning' to reduce the risk of dislodging it. You can also empty the bag and temporarily clamp off the tube before sexual activity. Taping the drainage tube to your abdomen can help to keep it out of the way. A pair of sexy crotchless pants over the top will help to hide it.
- if you are worried about incontinence of your bowels, a micro enema or anal plug may help; speak to a continence advisor for more information.



## MS and sexual response

### Some general advice on finding the best sexual position

For heterosexual couples, the ‘missionary’ position (man on top) can be difficult for women to achieve, especially those with disabilities. Experimenting with different sexual positions and varying your sexual routine can be invigorating. It’s also usually a lot of fun experimenting!

If full intercourse is difficult, be adventurous – there are plenty of ways of achieving pleasure without penetration.

*“My stamina is a lot less now and I cannot sustain any actions for any length of time as bits of me tire out. I have to change positions a lot (although generally there are not a lot of complaints about this!)”*

Karen

*“Sex is harder for me now as I get tired quicker and find a lot of positions impossible. We have had to adapt and experiment with new ideas and positions. Kisses and cuddles have become an important part of our relationship and something I really enjoy.”*

Julie

### Medication and sexual response

Some medications that are prescribed to control MS symptoms can cause sexual problems as a side effect. For example an orgasm requires muscular contractions to take place. Muscle relaxant drugs are commonly used to decrease muscular contractions and so can affect your ability to achieve a pleasurable orgasm. Antidepressants can reduce your libido and delay orgasm. Whilst it may be difficult to change your medication, it is certainly worth discussing the options with your GP or MS specialist nurse if you feel that your sex life is being affected.

## Section 3:

### Self-esteem

MS can affect your sexual identity, confidence and self-esteem in many ways. You may feel less self-confident generally – perhaps you have had to give up activities that were an important part of your life and closely linked to your self-image. You may have undergone physical changes that affect how you view yourself – some women feel that their body has ‘let them down’. Perhaps you worry that you will be less attractive to your partner or a potential partner?

Below we offer some suggestions that may help improve your physical and psychological self-esteem and your capacity to be positive.

#### A positive outlook

For some women, living with MS can have a profound impact on how they feel; they see themselves somehow as a less ‘useful’ or productive member of society or fear becoming a burden. If you feel like this it is important to challenge these perceptions. Consider how you might replace them with more positive beliefs. It won’t happen overnight, but it is possible to change negative patterns of thinking and replace them with a more upbeat outlook.

**List your strengths:** it can be helpful to remind yourself of your core strengths and the things that you like about yourself – these won’t have changed, even though you have MS. List five things that you like about yourself as a person and ask family and friends to contribute their lists too – you might be surprised what they come up with! Keep a note of these and refer back to them whenever you need a confidence boost. It is also useful to start each day with a positive statement about yourself.





## Self-esteem

**Keep in touch:** don't cut yourself off from people just because you have MS. Try to keep in regular contact with friends, either face-to-face, over the phone or online social networking sites – a good old gossip can be a real mood booster and can help you to feel more connected to the outside world. If you find it difficult to get out, invite a friend round for a coffee or glass of wine.

**Learn a new skill:** perhaps you have space and time in your day to try something new. Learning a new skill can be great to boost self-esteem and can provide a real sense of achievement. It can also be a good way to get out of the house on a regular basis. If mobility is a problem, there are plenty of correspondence or online courses to choose from. Some courses are subsidised or even free for students receiving certain benefits.

**Volunteer:** helping others through volunteering can also help you to feel more positive about yourself. Perhaps you have a skill that would benefit other people or could be passed on to them, or perhaps you are willing to devote some of your time and effort to good causes. Contact local charities to see if you can support them in any way or check on the internet for projects in your area (see Section 6). You may also want to talk through your interests with your MS specialist nurse who will know what is available locally.

**Stay active:** many women feel good if they exercise regularly. It is well known that exercise can boost your mood, increase your energy levels and your self-esteem. An additional bonus is that it helps maintain a healthy weight and improved tone.

Women with MS can manage a range of exercise activities and some report that they have become fitter than they were before their diagnosis! The MS Trust DVD *Move it for MS!* and web-based *Exercises for people with MS* will get you started. If you want to go further the MS Trust web pages *Staying Active* will give you lots of ideas of sport and leisure activities. See Section 6 for more details.



## Self-esteem

*"I am quietly working on getting my confidence back – following a relapse it is hard going. I have a 13 month old baby so she is now getting me fit again as we go out power walking and I am finding that I am now losing weight and feeling fitter – my confidence is coming back."*

Suzanne

**Accentuate the positive:** it may help to focus on the good things in your life and concentrate on what you still enjoy doing. Although your life has changed, it is definitely not over. Know your limitations but never aim too low. Think about what you have enjoyed doing in the past as you may find that these activities are still enjoyable for you. It can help to keep a stock of comedy DVDs for when you are feeling down – laughter is a great tonic!

**Be realistic:** if your mood does not improve over a number of weeks and life is becoming a real struggle, don't suffer in silence. You may be suffering from clinical depression and will need some form of treatment. The first step is to talk to someone. It may be a family member or friend, your GP or MS specialist nurse. Particular signs to watch for are ongoing sadness and tearfulness, problems sleeping, changes to your appetite and general loss of enjoyment of life.

### Physical confidence

Many women find that their body image changes because they have MS. Being comfortable about your body and making the most of your best features together with staying as fit and healthy as you can is key. Forget the myth that you need a perfect face and figure to be sexually attractive. Let's face it – without a team of stylists and make-up artists and the help of plenty of airbrushing, even celebrities are far from perfect! Maximise the positive and minimise the negative; look at ways of disguising your problem areas and flaunting your assets.



## Self-esteem

*“When I feel reasonably OK I try to set aside time for me at weekends – full body scrubs, moisturising, nails, including nail varnish. After these I feel like a human. Give me a man – now!”*

Michelle

*“Buying yourself sexy lingerie might help boost your esteem. My partner urged me to break away from Markies functional black knickers for once ... and it worked. I felt better about myself!”*

Karen

There are plenty of simple things you can do to feel good about yourself:

- invite friends round to your house for an afternoon or evening of pampering treats, such as facials or manicures. You could club together to pay for a beauty therapist from a local salon to carry out the treatments, or ask everyone to bring along some beauty products and try treatments out on one another. Even something as simple as eyebrow shaping can make a real difference. Or, if you're feeling brave, try a wax!
- if you wear make-up, think about updating your look – many department stores offer free makeovers at the beauty counters or charge a small fee that is refundable if you purchase products.
- if you have always taken care of your appearance, then keep on doing this. There is no reason why you shouldn't spend time and money on yourself.
- treat yourself to a new perfume or gorgeous bath oil – being surrounded by lovely fragrances can have a really positive impact on mood.
- if your body shape has changed, adapt your clothing to focus on your most attractive features and to disguise tricky bits.



## Self-esteem

These may sound like relatively simple steps but they can make all the difference. Changing negative ideas you may have about your body image will take time, but if you begin to feel more confident in your appearance, this can provide a huge boost to your self-esteem.

*“This is me. I can’t do anything about it. Like it or lump it!”*

Michelle

*“In terms of enhancing sexuality, I like to do the same things as other women – buying new clothes, nice underwear, having nights in with my partner and spending time together – I have slowly learned to view myself as a woman WITH MS, rather than an ‘MS sufferer’ being my most important label.”*

Esther



## Section 4:

### Intimate relationships

Living with MS on a day-to-day basis can be stressful and create pressure or tension within relationships. But some women find that sharing the experience of living with MS brings a new closeness and depth to relationships. Some relationships are not strong enough to survive the diagnosis of MS. Some partners are unable to cope with all that it brings. In this section we consider the importance of good communication and highlight the value of maintaining intimacy, particularly when full sexual activity is not possible.

*“My partner tries to be optimistic for the future. He always helps me with anything I need. I think our relationship is stronger now as we always do everything together.”*

Irene

### Communicating with your partner

If you are experiencing sexual problems in your relationship then good communication is absolutely vital. This is easier said than done. Many of us find it really difficult to share a discussion about sexual matters and when someone has MS, it can make for an emotionally charged situation.

*“My husband said from the day I was diagnosed that we were in this together. He has always been there for me and during my bad days has been my rock. Our relationship is very good.”*

Julie

Opposite we offer some suggestions for discussing sexual problems in a positive and constructive way:



## Intimate relationships

**Don't put it off:** if you are experiencing sexual problems, the longer you leave it, the more difficult it will be to broach the subject. For example, if your libido is diminished or lost, it is tempting to avoid any intimate or sexual contact. This can be confusing for partners who may misinterpret this as rejection or failure on their part. They may feel resentful or hurt. It is better to be honest and to confront the situation together so that you can agree a plan of action.

*“All I can say is see what will help and don't let it cause the bad feelings and problems that doing nothing can cause.”*

Lora

**Plan ahead:** rather than bringing up the subject out of the blue, it may help to say that you would like to chat at a later time or date. Agree a convenient time and place to talk when you won't be disturbed. You may want to use books, publications, or videos to initiate a discussion. Consider the mood your partner is in and use your judgement. If it feels right to talk, then go for it.

**Take the initiative:** when partners seem to have lost interest in sex, it is good to find a time to discuss the matter in a calm and non-threatening way. You may be surprised at their reasons for avoiding sexual contact. If you have recently been diagnosed, they may simply need time to adjust to the new situation. Alternatively, they may be worried about hurting you if you have sex or may mistakenly believe that continuing to have sex can be harmful to your condition. An honest discussion can help to dispel any misunderstandings.

**Don't get things out of proportion:** sometimes you can lose your sense of perspective and imagine that your problems are more serious than they really are. The problems can grow in size in your head, but when you talk to your partner they may have a different perspective and feel that your difficulties are much less of an issue.



## Intimate relationships

*"I try to listen to my husband's problems and he to mine. Then we try to work out a solution."*

Julie

**Be sensitive:** if you have lost your ability to enjoy sex, explain to your partner that the problem is related to your MS and reassure them that it is not a result of any change in your feelings for them or their lack of sexual prowess. When discussing sexual or relationship issues, avoid accusing, criticising or blaming your partner: use phrases such as "I feel..." or "I would like..." instead of "you don't". Try to keep calm and listen to each other's feelings. If the discussion becomes heated, agree to stop and to resume at an agreed time.

**Keep your sense of humour:** a good sense of humour can work wonders when you are talking about sexual problems and sharing a laugh can help to bring you closer. Remember that sex is supposed to be fun!

*"My husband is a wonderful man with a wonderful sense of humour which has kept us both going during the bad times. We have our down days but I try not to let it affect me."*

Suzanne

**Think about what you want to say ahead of time:** you may want to prepare a script, practice on your own or, if you can, with a friend. Sometimes using pictures or illustrations can help when it is hard to put things into words. This may bolster your confidence and will help to ensure that you cover the points you want to discuss.

**Be realistic:** while some relationships become stronger after a diagnosis of MS, unfortunately, others fall apart. If you had problems in your relationship before your diagnosis, they will not disappear overnight and sadly, your partner may be incapable of providing the support you need. If this is the case, then you need to consider whether your relationship can



## Intimate relationships

survive. Professional counselling can help you to determine the best way forward. See Section 6 for more details.

**Be honest:** it is natural not to want to worry your partner too much but if you are really feeling down, you do need to be honest so that they understand what you are going through. Putting on a brave face can leave you feeling isolated and make others feel rejected or helpless. If you are going through a particularly bad patch, it could be useful to talk to your GP or MS specialist nurse.

**Make time for your partner:** some women say that MS can dominate a relationship and that over time, conversations and social excursions tend to focus on their condition and how it affects them. The other partner can feel excluded and may begin to feel that their needs are not being taken into account. Both you and your partner could draw up a wish list with ten things you would like the other to do for you, sexually and romantically. Then take it in turns to swap treats from the lists.

If you really find it difficult to talk about sexual issues, then write down how you feel and ask your partner to read it. Then agree to discuss the matters you have raised.

### Rediscovering intimacy

Intimacy means far more than just having penetrative sex. Physical intimacy such as hugging and stroking is an important element of any relationship, especially when full sexual contact is not possible. Emotional intimacy is also vital – this means sharing things with each other, spending time together and simply ‘being there’ for each other.

*“We now have a less physical, more gentle intimacy, more cuddles and we know we are there for each other.”*

Irene



## Intimate relationships

Maintaining or resuming intimacy can be difficult at times; here are some ideas you may find helpful:

- if you have stopped having sex, temporarily or over the longer term, your partner will need reassurance that you still love them and find them attractive. You can still show affection in many other ways. A kiss, a hug, a note or a few loving words sound simple, but they all show that you care and will help maintain the intimacy within your relationship.

*“When it is too painful to be active sexually, I try to caress, touch, hold and kiss to remind my husband I still need and want him.”*

Maz

- intimacy doesn't just happen – it needs to be worked at and not just in the context of sexual activity. Make an effort to spend time together; time that is intimate in a non-sexual way such as talking about your feelings, rather than just discussing daily mundane topics such as what you are having for supper. Try not to let your conversations revolve around MS too much.
- if you are resuming sexual contact after a break, be patient and take things slowly. Don't expect everything to be perfect straight away or to be the same as it has always been. If something doesn't work, be flexible and try an alternative approach. Restoring intimacy needs to come before sexual contact.
- be prepared for the fact that some sexual requests will be rejected – this doesn't mean that your partner is rejecting you as a person – they may need time to adjust to the new situation. Any change that needs to occur within your sexual relationship will take time and effort from both parties.



## Intimate relationships

*“Learn to laugh about it and not get too disappointed!”*

Ruth

- share with each other what feels pleasurable and what does not. Be prepared to experiment with different sexual positions and be creative in finding ways to give and receive pleasure. For some fun ideas, see Games to play in Section 6.

*“We talk a lot more about intimacy and sexual issues and what each other likes or dislikes. This has helped our relationship and brought us closer together.”*

Julie

- remember that if you don't have regular orgasms or penetrative sex, you're not unusual. There is no 'normal'; don't be misled by popular myths about sex. You can still experience sexual pleasure and intimacy through other forms of touch such as cuddling, caressing, massage etc.

*“I use my mouth rather than my hands as I don't have enough feeling in my fingers to 'do a good job'.”*

Jan

- if you are finding it difficult to resolve your problems, consider talking to your MS specialist nurse or another healthcare professional (see Section 5). They will have talked to others before you about the same problems and if they don't have the answer can refer you to someone who does.
- in some cases, it may be helpful to seek more specialist forms of counselling called psychosexual counselling. This involves assessment and management by a specialised sexual therapist. Your MS specialist nurse, GP or neurologist may refer you for this. Counselling will allow you to explore your feelings and any partner's, if wished, in a respectful and professional way. Emotions can be worked through in a non-judgmental way.



## Intimate relationships

### Starting new relationships

If you are not currently in a relationship, the fact that you have MS can affect your attitude towards meeting potential partners.

*“I think that trusting people and enjoying my sexuality were not huge issues for me but that the sadness my diagnosis caused made me feel less like embarking on new relationships and certainly less attractive. Only by chance did I find a kind, supportive partner who I felt comfortable with and they have helped me to feel much happier with these issues.”*

Esther

Some women with MS experience feelings of low self-esteem and lack of confidence, believing no one will want them because they have MS. These thoughts and beliefs affect behaviour and may result in a reluctance to flirt or start relationships. Others are unsure how to go about meeting a potential partner.

*“After I developed outwardly visible signs – dragging leg, walking using a stick and at times a wheelchair or scooter, droopy arms and sometimes jerky limbs, I felt that was it! I thought my chances of ever meeting a guy I liked who would ask me out were over. I didn’t feel like a fully functioning woman any more. I’d never had good body image anyway, and that put the lid on it – who would want me now? But two years ago I met a non-disabled older guy who asked me out. I couldn’t believe it! Since then, I’ve gone out with another guy, and am now in another new relationship! It has boosted my confidence a lot ... but for a while, I thought it was over.”*

Karen



## Intimate relationships

It can be difficult enough for anyone to find a new partner and having MS can make the process even more complicated. Some women with MS find that there are simply fewer opportunities to meet new partners – perhaps they have given up work and/or have cut back on their social life. However, many single women with MS do meet partners and go on to have long and successful relationships.

Below, we suggest some ways of meeting partners and how to talk to them about MS:

**Widen your horizons:** it is often easier to set your sights initially on meeting new friends in a social environment rather than looking for someone with whom you could have a sexual relationship or long-term commitment. As a way of meeting new people, it is worth considering joining a health club, enrolling on a course at a college, joining a musical group or taking part in volunteer work. There may be specific groups in your area that cater for the single person and organise social events - these can open the door for all sorts of new experiences. Your MS specialist nurse may be able to provide further information on this topic, or try searching the internet.

**Consider dating services:** if you want to meet a new partner, many women use personal ads, agencies or online dating services. Millions of people use online dating services; many sites are broad-based, with members coming from a variety of backgrounds looking for different types of relationships. Other sites are more specific, based on the type of members, interests, location, or relationship desired. Some dating sites allow you to browse for free for a limited amount of time and provide a mailbox so you do not need to disclose your personal e-mail address unless you want to. Safety is a really important issue - remember that not everyone is honest or trustworthy. Follow the advice given by the dating service.



## Intimate relationships

*“It took me a while to pluck up the courage to try dating websites, and I met a few frogs before I found some princes! I decided that, for me, free websites weren’t always a good idea – paying up front to be included implies a greater degree of commitment, making me feel more comfortable that someone else had the same motives as me! I’m always cautious, trust my gut reactions and take the time to get to know someone through the website, then by exchanging emails, before arranging to meet. Apart from anything else, when we meet face-to-face we have plenty to talk about.”*

Sarah

*“My advice would be to think about how you want to appear in your profile and what sort of relationship you’re looking for. Get a good friend to look at what you’ve written. I tried to be honest but you can’t expect the same from others! I prefer a relatively early face-to-face meeting as I feel nothing can beat it; it can be very disappointing to find that you just don’t gel with someone you felt compatible with after emailing for an extended period.”*

Anne

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

Trudie



## Intimate relationships

**Go online:** some women prefer to use chat rooms on the internet. These can be very diverse and open up a whole new world of communication with other people. Some use them to develop friendships, others want more than this and some chat rooms are specifically geared up for sexual encounters. There are also specific disability-related sites that allow you to post personal ads, or have free chat rooms and you may feel these are more appropriate for you.

*Partners have known of my MS in advance of a relationship. In two relationships I felt very supported so it highlighted the positives about our relationship. In one relationship, I felt patronised – ‘Look everyone – my girlfriend’s disabled and I’m OK about it’ so I guess it highlighted the negatives.”*

Jan

When you do meet somebody, if they are not already aware of your MS, it raises the dilemma ‘to tell or not to tell’. If you decide to tell, then you need to decide when to tell them. There is no right or wrong way to do this and to a certain extent, it’s a matter of what feels right for you. Some women prefer to be open about this from the outset, while others decide to wait until they know somebody better and feel more relaxed with them.

*“I don’t cover the MS up – it’s not fair to the other person.”*

Michelle

*“I wait until the second date before I tell. If I like someone enough to see them again, I reckon I should tell them I have MS. 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.”*

Emily



## Intimate relationships

There is no way of predicting how somebody will react – many people will take the news in their stride while others may need some time to absorb this new information. Realistically, it may affect the way that some people behave towards you. Their response will partly depend on how much they know about MS and it may be helpful to suggest that they read one of the MS Trust’s booklets, such as ***MS Explained*** so that they are aware of the facts (see Section 6).

*“If you are single, it is hard to broach the subject with a new partner. I could see that when I told people I had MS, some of them treated me differently. This put me off meeting new people.”*

Esther

## Section 5:

### Talking to healthcare professionals

When it comes to talking about sexual problems, it can feel like a conspiracy of silence: people with MS find it tricky to discuss their symptoms and healthcare staff can appear unwilling to enquire. The reasons behind this failure to communicate are mutual to both parties: embarrassment, lack of time, not knowing how to approach this sensitive subject and a belief that it is too intrusive a topic to mention. It is also true to say that in MS, the emphasis of care is often focused on other aspects of the condition, despite the fact that sexual problems are undoubtedly a key area of difficulty for many people.

*“Some women with MS are made to feel that sex is a luxury; others feel that healthcare professionals think disabled women don’t have sex.”*

Trudie

Many people find it difficult to talk about sexual problems with their partner or close friends, let alone a GP or their MS specialist nurse. However, the reality is that if you do not take the initiative, there is no guarantee that they will raise the topic. It has been shown that even simply talking about your sexual problems to a professional, or perhaps a non-judgmental friend, can be beneficial in itself and can make all the difference to how you feel about yourself.





## Talking to healthcare professionals

*“Talking to someone you aren’t so close to can actually be a good thing – after all, they aren’t emotionally linked to you and what you say won’t upset them or worry them on a personal level. When we talk to friends or family we worry that we are burdening them.”*

Esther

It is entirely natural to feel embarrassed talking about intimate details to a relative stranger, but remember that sexual problems are a legitimate consequence of MS and are managed in the same way as any other problem such as fatigue or muscle spasm. Many healthcare professionals are used to talking about such matters on a regular basis.

*“I feel that some members of the health profession have helped me a lot to deal with intimacy issues – combating depression, shyness and feelings of low self-esteem. However, no one has ever raised the issue of sexual dysfunction with me. I realise that discussing issues like this can embarrass some sufferers, and that they may prefer to deal with these issues in private, but I do think that patients need to know that it is OK to discuss such issues if they want. After all, if we can’t talk to the medical profession, how are we ever supposed to discuss things like this with partners?”*

Esther

Before you attend your appointment, it might be helpful to think about the actual words you are going to use when you are discussing sexual difficulties with a healthcare professional as you will probably need to be quite specific. Consider which words you are most comfortable with when talking about your genital area, perhaps ‘down below’, ‘nether regions’, ‘private parts’ and so on. If you choose words that you feel comfortable with, this may help you to relax. Using pictures or diagrams is an alternative way to explain difficult things.



## Talking to healthcare professionals

It can also be helpful to note down your problems and questions on a piece of paper as it is easy to forget important points when you are talking about a sensitive subject like sex. It may increase your confidence to rehearse what you are going to say.

*“I have approached various health professionals and none have taken up my problems and in some cases, reacted with embarrassment. Even when helpful, there is little experienced help to be had.”*

Marion

Unfortunately, it has to be said that not all healthcare professionals are comfortable, skilled or well informed about sex. If you are not receiving adequate support, ask to be referred to somebody with more experience in this area. Don't give up; help is out there, but you may need to be persistent!

The following healthcare professionals are accustomed to discussing sexual issues and may be worth talking to:

- MS specialist nurse
- district or practice nurse
- continence advisor
- physiotherapist
- occupational therapist
- GP
- sex therapist or counsellor
- urologist

A number of specialist sexual clinics are available within the NHS, although access to these may be limited and some areas of the country are better served than others. If you are referred to a sex therapist or counsellor, they may be able to prescribe drugs or treatments which are not routinely available.

**Remember that not all the sexual problems you may be experiencing will be caused by MS. They may be caused by other health-related conditions and it is important to consider this issue when talking with healthcare professionals.**



## Section 6:

### 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 head using the tips of their fingers, gently covering your whole head.
- Ask them to move around your front and sit on your lap facing you, placing one leg either side of you.
- Ask them to continue massaging your head and move down to your neck and shoulders.
- Ask them to delicately kiss your face as they do this.

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

- Slowly undress them.
- As you remove each piece of clothing, stroke and caress this part of their body.
- Stroke their 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 are going to do, or you may want to carry out this activity in silence.
- As you explore different parts of their body, you may want to ask them how they are feeling - is the touch or caress sensual?

Next time, swap roles and wear the blindfold while your partner undresses and explores you. You could also try this game with the undresser wearing the blindfold.



## Resources / Games to play

### **Sit down with your legs open as wide as you can and 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 to yours as possible so the tips of your noses touch.
- Move their hands in parallel up your legs to grasp the inside of your thighs halfway.
- 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.
- 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 while 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, they must not touch you with their hands.
- Ask them to blow on your genital area and to kiss you fleetingly over your pants.
- Ask them to play with you through your pants with their thumb and forefinger.

### **Sit on a chair with your head tilted backwards.**

- Ask your partner to undo your clothing to expose your neck and breasts.
- Then pass their fingers over your face stroking your forehead, cheekbones and nose.
- Ask them to wet their fingers and rub your lips.
- Lick your partner's fingers very slightly as they are doing this.
- Ask them to stroke your chin, move their fingers downwards and play with your neck and shoulders.



## Resources / Games to play

- Move their hands to your breasts and tell them to gently play with your nipples with moistened fingers.
- Ask them to kiss you deeply.

### **Ask your partner to take off all their clothes.**

- Using a baby's soft hairbrush, brush your partner all over.
- Try brushing downwards and upwards for different sensations.
- A stiffer brush will produce a stronger sensation, but beware of being too rough!

Ask him/her to return the compliment.



## Resources / Organisations

### Organisations

#### Sexual health

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

50 Featherstone Street

London EC1Y 8QU

0845 122 8690 (England, Scotland and Wales)

0845 122 8687 (N Ireland)

**[www.fpa.org.uk](http://www.fpa.org.uk)**

*Variety of information on sexual health including contraception, safe sex, and sex education.*

#### Counselling

##### **British Association for Sexual and Relationship Therapy**

BASRT

PO Box 13686

London

SW20 9ZH

0208 543 2707

**[www.basrt.org.uk](http://www.basrt.org.uk)**

*Professional organisation for sexual and relationship therapists. Can provide a list of accredited therapists in your area.*

#### Relate

Relate Central Office

Herbert Gray College

Little Church Street

Rugby CV21 3AP

0845 456 1310

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

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



## Resources / Organisations

### Self-help groups

#### **Outsiders Club**

The Outsiders  
4S Leroy House,  
435 Essex Road,  
London N1 3QP  
0207 354 8291

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

*Outsiders is a self-help group for people with physical and social disabilities seeking to gain more confidence and to find partners. Runs a user group for disabled women with sexual problems and a sex and disability helpline. The website has lots of practical advice and a range of leaflets.*

#### **Regard**

BM Regard  
London WC1N 3XX

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

*Regard aims to raise awareness of disability issues within the lesbian, gay, bisexual and transgendered communities and to raise awareness of sexuality issues within the disability communities.*

#### **London Lesbian and Gay Switchboard**

0207 837 7324

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

London helpline for lesbians, gay men and bisexuals.

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

*Lists lesbian, gay, bisexual and transgender regional helplines.*



## Resources / Organisations

### Volunteering

#### **Timebank**

2nd Floor

Downstream Building

1 London Bridge, SE1 9BG

0845 456 1668

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

*TimeBank UK is a national charity providing volunteers with information on voluntary work and volunteering projects in the UK & overseas.*

#### **Do-It**

YouthNet UK

First Floor

50 Featherstone Street

London EC1Y 8RT

[www.do-it.org.uk](http://www.do-it.org.uk)

*Provides details of UK volunteer vacancies.*

### Carer groups

#### **Princess Royal Trust for Carers**

London Office

Unit 14, Bourne Court

Southend Road, Woodford Green

Essex IG8 8HD

0844 800 4361

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

*Provides carer support services throughout the UK via a network of 129 independently managed Carers' Centres which are listed on the website.*

#### **Carers UK**

20 Great Dover Street, London SE1 4LX

0808 808 7777

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

*Organisation run by carers, providing support for carers.*



## Resources / Publications

### Publications

#### MS Trust publications you may find helpful

##### Books:

- MS explained
- Living with fatigue

##### Factsheets:

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

##### Exercise resources:

- Move it for MS!: a DVD of exercises for people with MS (charge of £1).
- Exercises for people with MS: an online resource. The exercises are arranged in categories based on how they are done and the problems they address [www.mstrust.org.uk/information/exercises](http://www.mstrust.org.uk/information/exercises)
- Staying Active: an online directory of sports and other activities [www.mstrust.org.uk/stayactive](http://www.mstrust.org.uk/stayactive)



## Resources / Other publications

### Other Publications

#### **The sex book**

Suzi Godson, Mel Agace, Robert Winston

Cassell Illustrated (2006). ISBN: 1844035115.

*Explores the subject of sex, health and sexuality in a straightforward and adventurous way.*

#### **The ultimate guide to sex and disability**

Miriam Kaufman, Cory Silverberg, Fran Odette.

Cleis Press (2007). ISBN: 1573443042.

*A self-help sex guide for people living with disabilities, chronic pain and illness.*

#### **Enabling romance:**

a guide to love, sex and relationships for people with disabilities (and the people who care about them)

Ken Kroll, Erica Levy Klein.

No Limits Communications (2001), ISBN: 0971284202.

*This book covers sexual stereotypes, building self-esteem, reproduction, and sexuality for people with disabilities and their partners.*

#### **My secret garden**

Nancy Friday

Pocket Books; Reissue edition (5 Feb 2008), ISBN: 1416567011.

*A compilation of women's fantasies.*



## Resources / Sex aids

### Sex aids

#### **Ann Summers**

Gold Group House

Godstone Road

Whyteleafe

Surrey CR3 0GG

0845 456 6948

[www.annsummers.com](http://www.annsummers.com)

*Website, mail-order catalogue and chain of stores throughout UK.*

#### **Beecourse**

PO Box 1824

Andover

Hants SP11 7ZJ

01264 358853

[www.beecourse.com](http://www.beecourse.com)

*Website and mail-order catalogue offering a wide range of sex aids.*

#### **Emotional Bliss**

0870 041 0022

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

*Website and telephone orders. A range of anatomically designed intimate massagers.*

#### **Love Honey**

Unit A, Locksbrook Road

Bath

Somerset BA1 3EU

0800 915 6635

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

*Website and mail-order catalogue.*



## Resources / Sex aids

### **Sh!**

Sh! Mail Order  
374 Station Road  
London. E7 0AB  
0845 868 9599

[www.sh-womenstore.com](http://www.sh-womenstore.com)

*Website, mail-order catalogue and London shops for women.*

### **Spokz**

2 Jordan Croft  
Fradley  
Lichfield  
WS13 8PN  
0845 257 7496

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

Website includes a range of sex aid products for people with disabilities.



## Section 7:

### The partner's perspective

This section is intended for the partner of a woman who has MS. It aims to give you a better understanding of how MS can affect sexuality and intimacy and offers tips to help you look after yourself and your partner, talk about this sensitive subject and work together.

MS can be a very difficult condition to live with, not only for your partner, but also for you. The chances are that since your partner was diagnosed, both your lives have changed to some extent – perhaps dramatically – and your relationship may also have been affected.

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

Judith

*“It has shocked him, believing I would always be strong and there for him. We are not so close anymore – I try and hide some of my problems from him as I don't want him to be embarrassed for me.”*

Maz

Being the partner of someone with MS can be very challenging and you may be experiencing a whole range of feelings that are affecting you either physically and/or emotionally. It can be difficult to know how to support somebody with MS – perhaps you feel unsure about what to say or how to comfort your partner? Unfortunately, there are no easy answers, but the very



## The partner's perspective

fact that you are reading this shows that you care and want to understand what is best for your partner and your life together.

### Adjusting to change

MS can affect many aspects of life. Your partner may have become less self-sufficient and more dependent upon you. Maybe she has had to give up her job and you are now the sole breadwinner, with all the added responsibility that this brings.

Your partner may have changed as a person – perhaps she has become less confident or less positive in her outlook. She may find it difficult to believe that anyone can still find her sexually attractive or she may feel like something of a burden to you. She may feel sexually vulnerable and need constant reassurance.

*“I know she feels she can't fully fulfil her part in this relationship and she does see the effect it has and is very self-conscious. She has very low periods where her self image/ confidence is at breaking point. She gets very questioning and jealous of my abilities as an able-bodied person. She has to be encouraged more to attempt to try things to build her self-confidence up.”*

Grace, partner

Your partner may also have undergone some physical changes. She may have to cope with unpleasant symptoms and may be less mobile than she used to be. Perhaps she has to depend on you for more of her daily needs and it may be that you have had to become involved with aspects of her care that make you feel less of a partner and more of a carer. This can have a profound effect on the way a couple view each other sexually. Just because you are a partner does not mean that you have to become a 'carer'. It is important that you are both able to feel a sense of independence and autonomy. The ability to do that will vary depending on your circumstances and you may have to enlist the support of others to make it possible. Talk to your partner's MS specialist nurse or social worker to see what options are available to support you both.



## The partner's perspective

*"I feel I have become more dependant on my husband to help with things when I am having a bad day. This can be strange because he becomes a carer, which is a strange relationship to have with someone you love."*

Julie

Many people take these changes in their stride but others experience a range of emotions. You may feel anxious about what the future holds. Perhaps you feel angry and frustrated that your life has been disrupted? Resentful that life seems to revolve around the needs of your partner. Or guilty that you struggle to feel the same way about your partner now that she has MS? Rest assured that these feelings are entirely normal and you are certainly not the only person to feel this way.

### What can you do to help?

Just being there to provide support can be a huge benefit for your partner. On the whole, it is best to take your cue from your partner. MS is a variable condition and symptoms can come and go. She may feel much stronger and more positive on some days, while on others, she may need a great deal of support and sympathy. Most women with MS want to be treated as a woman and not a patient or just a person with MS.

Although you may feel that you need to have all the perfect responses for your partner, simply offering to listen can be just as supportive and reassuring. There may be certain topics that you find too difficult to listen to. Or there may be times when you are not in the mood or feel that you have heard enough. Suggesting a break from listening and arranging to pick up where you left off later can give you breathing space and time to think things over.

In turn, if you partner sees that they are able to talk freely, they will be more open to listening when you need to talk.



## The partner's perspective

*"It is so hard to ask our partner questions sometimes because 'we should know'. We don't always know! Please don't get angry if we don't react like you think we should ... we just might not understand."*

Jon, partner

It can be helpful to learn more about MS so that you understand what your partner is going through. For example, it is important to realise that some symptoms of MS are 'silent' - they cannot be seen on the outside and are not obvious to other people - but this certainly doesn't make them any less real or difficult to cope with. A classic example of this is fatigue. Fatigue is both a legitimate and common symptom of MS that can impact on many aspects of day-to-day life, so if your partner complains of feeling exhausted, she is not making excuses.

*"My partner... is still learning about MS. He is surprised sometimes at how quickly I become fatigued - but he learns fast and does not put me in any situations (parties for example) where I feel tired or stressed."*

Esther

Try not to feel rejected if your partner is unwilling to have sex – it is unlikely to be a reflection of her feelings for you. MS can have a major impact on the way a woman responds sexually and these effects may be temporary or longer-term. Section 2 of this book explains how MS affects sexuality. If sex is off the agenda for a while, it is still important to show affection and there are plenty of other ways to stay close as a couple.

*"There is always the underlying fear that it's something to do with oneself. This sounds rather self-centred, but her disinterest in sex (for MS reasons) undermines my own self confidence."*

David, partner



## The partner's perspective

If you are struggling to cope in your role as a carer, you may find it helpful to contact one of the relevant organisations for carers (see Section 6).

Many couples find that working through their problems together can bring them closer and strengthen their relationship but in some cases, relationship or sexual counselling can be the best way forward. Sources of help can be found in Section 6. Some couples find that living with MS can put their relationship under initial pressure but that after a period of adjustment, they come out of it feeling closer than ever before. There is no way of predicting how a relationship will be affected.

*"I think our relationship is stronger now as we always do everything together. We now have more gentle intimacy, more cuddles and we know that we are there for each other."*

Irene

## Looking after yourself

To support your partner, you need to be in good shape so remember to take care of yourself! The following general advice for healthy living can help to keep your energy levels high:

- get plenty of sleep.
- eat healthily.
- drink plenty of water at regular intervals throughout the day.
- make time for yourself when you can socialise and relax.
- take regular exercise – this doesn't necessarily mean you have to sign up to a gym – a brisk 20-minute walk can be just as beneficial.

Remember that even though your partner is the one who has MS, you are both living with it and your needs are important too.

## About the authors

### Nicki Ward-Abel

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Nicki has worked with people affected by MS for over 10 years and has a special interest in providing support for sexual difficulties. Her experience of dealing with these sensitive issues highlighted the need for a book for women that not only describes how MS affects sexuality but also offers positive and practical advice.

### Janice Sykes

Information Officer, MS Trust

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

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

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