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# MS, SEX, SEXUALITY and INTIMACY

A Consensus Guide  
for Healthcare Professionals by  
Healthcare Professionals

Biogen Idec have paid for the design, development and printing of this item, but have generated none of the content.



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A person's right to a good quality sex life:

- The right to love and be loved
- The right to touch and be touched
- The right to share intimacy
- The right to be a sexual human being



"I'm 100% behind the idea of promoting disabled people as ordinary, sexy, passionate beings."

Lesley Betts, person with MS

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“Don’t assume that somebody is or isn’t having sex. Open the door. Maybe say something like: ‘Some of my patients find that sex is an issue for them and they find it helpful to discuss this.’”

## Introduction

Don’t assume that somebody is or isn’t having sex. Open the door. Maybe say something like: ‘Some of my patients find that sex is an issue for them and they find it helpful to discuss this. If you feel this way I would be very happy to discuss this issue with you.’ This enables someone to talk about this issue and also normalises it, so the patient can see that they are not the only one.

Don’t assume that just because a person appears confident in certain areas of their life that they will be confident enough to bring up the issue of sex and sexuality with a doctor or HCP. They may not.

It is your job to give the patient permission to bring up this subject. This is a very important role for the HCP. It can be difficult enough for a non-disabled person to talk about sex, let alone when MS is part of the situation as well.

You don’t have to know all the answers. You need to know how to listen, how to open the conversation and when to refer somebody on – or say that you don’t know the answer but you will find out. Or maybe there is somebody else in your practice who has a bit more experience.

Be honest with yourself about what stereotypes or hang-ups you have that could become barriers between you and your clients. Look at how you deal with these barriers – counselling for health professionals is very valuable, as is peer group work and teamwork. Make discussing sex and sexuality something that you as a team do, so that you can gain support and information from each other.

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# 1 Background to this guide

There is a wealth of information about sex and sexuality, implying that it's easy to talk about, find out about, and that everyone is having it without difficulty, shame or guilt. But we know that this is not the case for men and women affected by MS. Sexual health and sexual wellbeing are essential aspects of MS care and management if patients are to have a good quality of life.

Sexuality connects us to a deeply important part of ourselves; it is a universal concept, common to all human beings, whether experienced or inexperienced, regardless of age, gender or ethnicity. Consultations with healthcare professionals (HCPs) can provide a confidential space to discuss sexual health problems.

Intimacy means different things to different people at different times. It changes as the individual is exposed to different experiences like disease and ageing. Intimacy can be cognitive – when two people exchange thoughts, share ideas and enjoy similarities and differences of opinion. Intimacy can involve mutual activities. There is also sexual intimacy, but this is so much more than sexual intercourse.

Terms associated with sexual health are often misunderstood or misinterpreted. Sexuality has lost its broad meaning and is now commonly used to identify an individual's sexual preference. This often puts the HCP off asking about issues involving the word 'sexuality', because it is often misconstrued by the patient.

But sexuality is so much more. As Girts (1990) says: 'sex is something we do and sexuality is something we are.'

This is important; it demonstrates that whilst sexuality includes sex it is more than the act of intercourse. People are sexual beings from birth to death; sexuality is a complex concept to articulate and often generates a highly personalised meaning. Like intimacy, it is dynamic, changing over time and sometimes as a response to life experience. Sexuality is a personal journey over the course of a lifetime and however it changes, it is important to health and wellbeing.

The World Health Organization (WHO, 2002) defines it this way:

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, roles and relationships. While sexuality can include all these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, physiological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.”

As specialists in regular contact with people with MS, we have an obligation to enquire about any sexual difficulties the patient is experiencing.

“Sex is something we do and sexuality is something we are.”

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How can we claim to provide holistic care if we are not assessing sexuality and intimacy? We should not leave it to 'someone else' to explore. NICE guidelines for the management of multiple sclerosis in primary and secondary care (NICE, 2014) state:

"Every person (or couple) with persisting sexual dysfunction should be offered the opportunity to see a specialist (with particular expertise in sexual problems associated with neurological disease) and offered, as appropriate, advice on lubricants and the use of sexual aids, and other advice to ameliorate their sexual dysfunction."

Sexual wellbeing refers to the patient's perception of their sexuality, sexual life and sexual relationships. It is important that people feel they have good sexual wellbeing if they are to live with a good quality of life.

As MS nurses, we can't, of course, be specialists in every aspect of care. But we can provide specific advice and suggestions to benefit someone with MS. It is understandable that many clinicians, nurses or HCPs feel hesitant about broaching this subject, but this discomfort can be eased by reading, listening to experts, becoming familiar with the language involved and starting to discuss and 'prescribe' sexual treatment or management by reflecting real scenarios with colleagues.

"Sexual wellbeing refers to the patient's perception of their sexuality, sexual life, and sexual relationships. It is important that people feel they have good sexual wellbeing if they are to live with a good quality of life."

### Special thanks:

Reviewed by **Simon Webster, MS Trust**

**Lesley Betts and John Greenwood**

**Alex Cowan**

**Birmingham Spokz People**

**Oyster Healthcare Communications**

## Authors

**Nicki Ward-Abel** RGN, BSc (Hons), Lecturer Practitioner, Birmingham City University and Queen Elizabeth Hospital, Birmingham

**John Pohorely** RGN, RMN, MS Specialist Nurse, Frimley Park NHS Trust, Surrey

**Helena Brown** RGN, BSc (Hons), MS Specialist Nurse, Walthamstow

**Sian Locke** RGN, BSc (Hons), MS Clinical Nurse Specialist, The Helen Durham Centre, Cardiff and Vale

**Lesley Catterall** RGN, MS Specialist Nurse, Bletchley Community Hospital, Milton Keynes

**Katrina Potter** RGN, BSc (Hons), MS Specialist Nurse for Kent Community Health

**Helen Owen** RN Dip, MS Specialist Nurse, Morriston Hospital, Abertawe Bro Morgannwg University Health Board

**Emma Matthews** RN, BSc (Hons), MS Clinical Nurse Specialist, Northampton General Hospital

**Alison Carolan** RMN, CAT Dip, MSc, MS Mental Health Nurse, Kings College Hospital, London

**Denise Middleton** Dip COT SROT, BA (Hons), MS Clinical Specialist, Milton Keynes Community Health Services

**Annette Leach** RGN, BSc (Hons), MS Nurse Specialist, Royal Berkshire Hospital, Reading

**Susan Duplock** RGN, MS Nurse Specialist, Royal Berkshire Hospital, Reading

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## Why HCPs need this guide

Research suggests HCPs generally feel uncomfortable discussing sexuality. They lack knowledge, education and training so they do not assess, teach, support or counsel patients about it. In 2013, the MS Trust ran an educational 'masterclass' in London, focusing on MS-related sexuality, which was attended by a range of experienced UK health and social care professionals who had an interest in this sensitive area of care. This masterclass concluded MS specialists should be better informed about sexual health and wellbeing.

'MS, Sex, Sexuality and Intimacy' focuses on people affected by MS in a more holistic way. Personal factors and a lack of specific knowledge and skills block HCPs from addressing sexuality and intimacy in the MS population. Some lack confidence discussing sexual issues, even if they know how much these affect an individual's quality of life. This guide covers cultural differences, the sexuality of gay, straight, bisexual and older people. It considers professional conduct, law and ethics, education and provides resources on sexual dysfunction, intimacy, sexual relationships and sexual identity. It will appeal to all HCPs, not just specialist nurses.

This guide benefits enormously from the advice and experience of MS patients who have been, and will continue to be, involved at all stages. Lesley Betts, featured on the cover, has contributed one of the three case studies that show the unique nature of every individual's intimate life. The case studies and involvement of people with MS also demonstrate how much resilience, creativity, honesty and commonsense is called for in the face of constant challenges.

### It will enable you to:

- discuss key concepts of sexual health and wellbeing
- associate how living with MS can directly or indirectly affect sexual health and wellbeing
- identify the right sexual assessment tools
- explore how a sexual history is taken
- communicate, regarding sexuality, with more confidence
- propose appropriate, effective strategies for promoting sexual health and wellbeing
- support specialists as they discuss these sensitive issues
- identify ways you can develop your skills and knowledge of this area of care.

It will be updated on an ongoing basis.

### HCP self-assessment checklist

Self-assessment will be a beneficial feature of this resource, allowing the HCP to be actively involved in the evaluation of their learning. A checklist will be added to a future edition of the guide. It will enable the HCP to identify strengths and weaknesses in their knowledge and understanding of sex, sexuality and intimacy for people with MS. Assessing one's own learning needs is motivating in itself and it is more likely there will be a change in attitudes and behaviour. Accompanying the checklist will be a framework for an action plan to help the HCP target their current and future needs and identify how those will be addressed.

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“How can we claim to provide holistic care if we are not assessing aspects of sexuality and intimacy..we have a duty, even an obligation, to enquire.”

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## 2 Defining 'normal' sexual function

Sexual expression is one of the most basic human needs, which persists despite disability or illness (Maslow, 1954). Sexuality is a vital and integral part of being human (WHO, 2002). It directly affects an individual's quality of life and there is a clear connection between sexuality and health (WHO, 2002). Sexuality is what makes us who and what we are. However, sexuality is not just about the sexual act or sexual activity; it is so much more than this, whether in health or illness.

The sexual response cycle is well documented. Originally researched by Masters and Johnson, it is a sequence of physical and emotional changes that occur as a person becomes sexually aroused. Understanding each phase helps partners better understand one another's bodies and sexual responses, enhancing their sexual experience. But there are still many myths and misconceptions about sex. The HCP needs to educate the patient and ensure he or she has an accurate and sound knowledge of sexual function.

Kaplan (1979) added to Masters and Johnson's work with three phases of desire, arousal and orgasm. Desire is particularly important in considering women's response. There are differences between genders – men are more likely to have sex for physical reasons and women for non-sexual and emotional reasons. (Meston & Buss, 2007)

Masters and Johnson (1966) created the first model for the human sexual response cycle through careful observations within a laboratory, of sexual intimacy and sexual intercourse between men and women. This work was then built upon by Kaplan (1979) who added the concept of desire before arousal and

condensed the sexual response into three phases of desire, arousal and orgasm. Kaplan's addition of 'desire' is a particularly important concept to consider when considering the female response. She wanted her model to reflect that, for women, desire is important because it leads to an increase in sexual tension, and thus arousal. The desire leads to arousal through touch, imagery, and other stimulation; this is called the plateau phase. Eventually the arousal escalates to orgasm and a release of sexual tension.

There are many critics of these models of sexual response, not least as a result of the work of Meston & Buss (2007) who conducted two pieces of research to explore the reasons why people have sex. It concluded that there were four main reasons:

- physical
- goal attainment
- emotional
- insecurity.

There were significant differences between genders that are essential to note as they help us begin to understand significant differences between the male and the female sexual response. Men were significantly more likely to have sex for physical reasons: "the person had a desirable body"; "the person was too "hot" (sexy) to resist" and for opportunistic reasons: "the person was available"; "the person had too much to drink and I was able to take advantage of them." Men also gave greater reasons for sexual pleasure: "I wanted to achieve an orgasm" and "It feels good" to increase their social status: "I wanted to enhance my reputation"; "I wanted to brag to my friends about my conquests" and to gain reference experiences: "I needed another notch on my belt"; "I wanted to improve my sexual

skills," and finally for practical, utilitarian reasons: "I wanted to change the topic of conversation"; "I wanted to improve my sexual skills." Women were more likely to have sex for non-sexual and emotional reasons, such as: "I wanted to feel feminine"; "I wanted to express my love for the person"; "I realised that I was in love."

To understand the female response even more, you may wish to read the work of Rosemary Basson who listened to patients with spinal cord injury. Through this she concluded that women can feel spontaneous desire at the start of a relationship, but when relationships become more long term, any sexual encounter tends to start from a 'intimacy' desire rather than a 'sexual' desire (which is more likely to influence men). They often begin to feel sexually aroused once sexual contact has begun.

"Basson's work has a major impact on how clinicians treat women in terms of reassuring women, educating women and intervening to help them deal with their sexual difficulties," says Sandra Leiblum, Director of the Center for Sexual and Relational Health at UMDNJ-Robert Wood Johnson Medical School in Piscataway, NJ, USA. Leiblum.

Within this guide, normal sexual function covers gay, lesbian and heterosexual patients and partners.

### LINKS

Sexual arousal NHS choices [www.nhs.uk](http://www.nhs.uk)

For more on Basson's work [www.thelancet.com](http://www.thelancet.com)

History of sex models [nursingplanet.com](http://nursingplanet.com)

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## Sexual response cycle

There are four phases, experienced by men and women.

### Phase 1: Excitement

This phase can last from minutes to several hours:

- Muscle tension increases
- Heart rate increases
- Breathing speeds up
- Skin may become flushed
- Nipples become hard or erect
- Bloodflow to the genitals increases, resulting in swelling (women – clitoris and labia minora; men – erection of the penis)
- Vaginal lubrication begins
- The woman's breasts become fuller and the vaginal walls begin to swell
- The man's testicles swell, the scrotum tightens and he begins to secrete a lubricating liquid

### Phase 2: Plateau

General characteristics of this phase extend to the brink of orgasm:

- Phase 1 changes are intensified
- The vagina continues to swell due to the increased blood flow and the vaginal walls turn purple
- The woman's clitoris becomes highly sensitive, even painful to touch and retracts under the clitoral hood to avoid direct stimulation from the penis
- The man's testicles withdraw up into the scrotum
- Breathing, heart rate and blood pressure increase further
- Muscle spasms may begin in the feet, face and hands
- Tension in the muscles increases

### Phase 3: Orgasm

This phase is the climax of the cycle – the shortest phase – generally lasting seconds:

- Involuntary muscle contractions begin
- Heart rate, breathing and blood pressure are at the highest level
- Muscles in the feet spasm
- There is a sudden, strong release of sexual tension
- The woman's vaginal muscles contract and the uterus goes into rhythmical contractions
- The man's penis contracts rhythmically at the base and ejaculation occurs
- A sex flush/rash may appear over the entire body

### Phase 4: Resolution

During this phase, the body slowly returns to its normal level of function. Swelling and erect parts subside in colour and size. A general sense of wellbeing, intimacy and fatigue occurs. Some women may return to the orgasm phase for further stimulation and multiple orgasm. Men need recovery time after orgasm, during which they will be unable to reach orgasm again. The duration of this phase varies from person to person.

#### LINKS

Sexuality & MS: a guide for women [www.mstrust.org.uk](http://www.mstrust.org.uk)

Sexuality & MS: a guide for men [www.mstrust.org.uk](http://www.mstrust.org.uk)

Sex, intimacy & relationships [www.mssociety.org.uk](http://www.mssociety.org.uk)

Getting the most out of Psychosexual Therapy, understanding sexual response, Porterbrook Clinic, Sheffield Care Trust [shsc.nhs.uk](http://shsc.nhs.uk)

Female Reproductive System [www.innerbody.com](http://www.innerbody.com)

Male Reproductive System – Medical Animation [ebco.smartimagebase.com](http://ebco.smartimagebase.com)

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## Sexual dysfunction

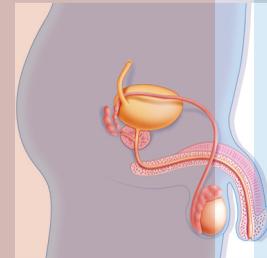
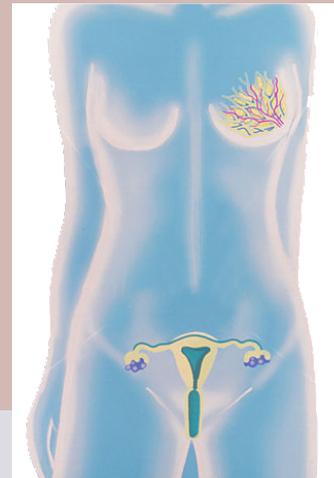
Approximately 22% of 40-year-old men and 50% of 70-year-old men experience erectile dysfunction. At least 21.7% of sexually active men experience premature ejaculation.

Studies show that up to 40% of women experience loss of libido. Delayed or absent orgasm is also very common, but the actual percentage of women is unknown.

It is widely accepted that erectile dysfunction is a sentinel marker and predictor of coronary heart disease and metabolic syndrome, especially in aging men (O’Kane and Jackson 2001). Erectile dysfunction and heart disease have common and shared risk factors: diabetes mellitus, hypertension, dyslipidaemia and smoking cigarettes.

## The normal female sexual response and the nervous system

Physiologically, the sexual response in women is similar to men. The vasocongestive response results in an increase in pelvic and vaginal blood flow as well as transudative vaginal lubrication together with clitoral and labial engorgement. The production of genital lubricating fluid is not only necessary to facilitate penile-vaginal penetration, but also appears to be important to how a woman perceives her own level of arousal; so that when a poor lubrication response occurs she may not feel sexually aroused. This has clear implications for women with MS who have a decreased or absent vaginal response.



[Click here for references](#)

## The normal male sexual response and the nervous system

**1. Sexual desire** is multifaceted and as such is much more than the biological drive for sexual activity. It has a complex interaction between the biological (neuroendocrine), psychological (cognitive & affective) social (relationship) & cultural (religious upbringing and societal norms) (Kaplan, 1979).

**2. Penile erection** is principally controlled by a pair of parasympathetic nerves from S2-S4. It is a haemodynamic event regulated by smooth muscle relaxation. It occurs following a series of integrated vascular processes, resulting in the accumulation of blood under pressure and end – organ rigidity. This vasocongestive response is mediated via the autonomic nervous system. A number of neurotransmitters are also involved in the erectile response; the most important appears to be nitric oxide induced cyclic GMP (cGMP) which causes smooth muscle relaxation in the penile corpora cavernosa. Detumescence occurs when cGMP is broken down by the enzyme phosphodiesterase (PDE) type 5. This is the enzyme which the majority of the current oral treatments for erectile dysfunction aim to target and inhibit.

**3. Ejaculation** has two phases – emission and expulsion. The emission phase is governed by the sympathetic nervous system. The ejaculatory phase is controlled by the sympathetic nerves from T11-L2.

**4. Orgasm** is controlled by the autonomic nervous system and involves smooth muscle contractions of the accessory sexual organs, contraction of the urethral bulb and the perineum, rhythmic contractions of the pelvic floor and ejaculation of semen.

**5. Detumescence** is the result of sympathetic discharge during ejaculation again at T11-L2 and the cessation of neurotransmitters. These levels are important to consider when assessing men with MS who have developed spinal lesions

### LINKS

For further explanation of male and female genital organs [www.innerbody.com](http://www.innerbody.com), [ebSCO.smartimagebase.com](http://ebSCO.smartimagebase.com)

Causes of orgasm problems in women [www.nhs.uk](http://www.nhs.uk)

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“People with MS often struggle with altered perception of themselves, with reduced self-esteem and self-worth, worried whether their partner will still find them attractive.”

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## 3 MS-related sexual dysfunction

Up to two thirds of men and women with MS have difficulties with sex. It is estimated that 45-70% of women and 50-73% of men with MS experience sexual difficulties (Demirkiran et al, 2006). Compared to the general population, this is a high incidence of sexual dysfunction.

Foley and Werner (2000) divide sexual dysfunction in MS into three categories.

### Why do people with MS experience sexual difficulties?

#### Primary

As a direct result of MS: plaques in the brain stem, lumbar sacral spinal cord; the amygdala nucleus of the hypothalamus, frontal and temporal lobes can affect sexual response and intimate feelings.

#### Secondary

Non-sexual MS symptoms affect sexual response or sexual activity. Women also experience ageing/menopause, which can induce certain vaginal dryness and lowered libido.

#### Tertiary

These are caused by the cultural, psychological, emotional and social aspects of living with MS (Foley and Werner, 2000).

#### LINKS

Sexual Problems [www.nationalmssociety.org](http://www.nationalmssociety.org)

Sexual problems affecting women [www.mssociety.org.uk](http://www.mssociety.org.uk)

A guide for women [www.mstrust.org.uk](http://www.mstrust.org.uk)

MS International Foundation 2005. Intimacy and Sexuality. MS In Focus. Issue 6 [www.msif.org](http://www.msif.org)

It is estimated that

50–73% of men with MS experience sexual difficulties

45–70% of women with MS experience sexual difficulties

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## Primary sexual dysfunction

Stems from changes to the nervous system that impair sexual response and/or sexual feelings.

### Males with MS can experience

- Erectile dysfunction (19.4-75%)
- Reduced libido (11-39.5%)
- Decreased genital sensation (35.9%)
- Failure to ejaculate (13.2-29.6%)
- Too long to ejaculate (9.7-23.2%)
- Difficulty masturbating (23.2%)

### Females with MS can experience

- Reduced libido (31.4-61%)
- Impaired vaginal sensation (19.8-61%)
- Difficulty with orgasm (24.3-54%)
- Decreased vaginal lubrication (19.4-46%)
- Difficulty masturbating (15.6%)
- Painful intercourse (17.9%)

### Altered/impaired genital sensation

This is common in MS. Many lose sensation in the genitals, which significantly affects libido and possibility of orgasm. Alternatively, patients may experience heightened sensitivity, experiencing uncomfortable genital disturbance, including burning, pain and tingling. This is less common and is probably due to lesions within the spinal cord.

### Orgasmic dysfunction

Orgasm depends on intact central nervous system pathways in the brain and pathways in the sacral, thoracic and cervical parts of the spinal cord. If these pathways are disrupted by plaques, sensation and orgasm can be altered or absent.

### Lowered libido

Slow arousal time, reduced libido or desire and altered orgasmic response are common. Libido can also be affected by lesions within the brain, particularly in the temporal lobe.

These symptoms may be caused by MS, but it is also essential to consider the side effects of certain drug therapies or psychological problems.

#### LINKS

Simon Webster, 2011 MS Trust. Sex and MS: a guide for men [www.mstrust.org.uk](http://www.mstrust.org.uk)

Sexual problems affecting men with MS [www.mssociety.org.uk](http://www.mssociety.org.uk)

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## Secondary sexual dysfunction

Non-sexual MS symptoms that affect the sexual response or someone's ability to be sexually active.

Mood alteration  
 Fatigue  
 Contenance  
 Constipation  
 Pain  
 Cognition changes  
 Muscle weakness  
 Tremor  
 Visual impairment

Someone with MS may struggle to come to terms with his or her condition. They may fear the future, or develop low self-esteem, both of which may affect relationships. Partners, too, have to come to terms with the diagnosis and its consequences. Stress, depression and anxiety all damage relationships by closing down communication. These are commonly experienced by people with MS. When someone is depressed, it is natural to withdraw from others. But open and honest discussion is vital at this time.

Someone with MS can shun physical contact – too tired for sex, particularly in the evenings. So the partner feels unattractive and even more strain is placed on the relationship. This can reduce sexual desire, but often couples do not talk about it.

Some medication can also affect the sexual response (more on this in Section 8).



## Tertiary sexual dysfunction

Caused by the cultural, psychological, emotional and social aspects of living with MS.

Low self-esteem  
 Poor self-confidence and self-worth  
 Apprehension about body image  
 Difficulties finding a partner  
 Depressive symptoms  
 Anxiety  
 Problems with communication and cognition

### LINKS

Talking about sexual dysfunction and MS

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

Sex and relationships [www.mssociety.org.uk](http://www.mssociety.org.uk)

Fatigue Management booklet [www.mstrust.org.uk](http://www.mstrust.org.uk)

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## Body image

Anyone with MS may experience doubts about body image, even if their disability is mild. They might question their attractiveness and feel less confident, leading to worries about physical deficiencies, which in turn cause sexual problems (Pfaffenberger et al, 2011).

Body image has been described as the mental picture of ourselves (Schilder, 1935). It is developed during childhood and refined during adult life. Body image falls into three key areas: the body ideal, the body we would like; the body presentation, which we show others; and body reality, which is the body as it really is. We present ourselves through clothes, cosmetics or 'camouflage', in order to achieve the desired appearance.

Body image can be affected by the level of support a person receives, or by how well they adapt to the challenges of an unpredictable disease and opinions of others (Ward-Abel, 2007). The impact of altered body image on self-worth is like grief, causing depression and isolation (Price, 1990). People with MS often struggle with reduced self-esteem and self-worth, worrying whether their partner still finds them attractive. This can be exacerbated if the partner is a carer as well as a lover (McCabe, 2002).

Within society, the favoured body image is physically attractive, young and healthy. Liddiard (2011) proposes 'ableism', a set of beliefs and structures in which able-bodied people are considered the 'norm' and disability diminishes a person's value in society. Liddiard's small

“People with MS often struggle with altered perception of themselves, with reduced self-esteem and self-worth, worried whether their partner will still find them attractive.”



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“Body image has been described as the mental picture of ourselves.”

qualitative study (2011) found male and female disabled people felt disempowered by society's sexual 'norms'. Poor body image had a direct association with feelings of sexual inadequacy.

MS can cause apparent physical disability, such as ataxic gait, but it can also cause cognitive problems or fatigue, which determine self-image (Ward-Abel & Hall, 2012). MS can cause bladder and bowel issues sometimes resulting in incontinence. Many become embarrassed and feel 'childlike' because of this lack of control. It negatively affects the way many feel about themselves and how they look; some have to change the way they dress to accommodate their difficulties. Many are too embarrassed to seek help even though there are strategies available that can help. The fear of urinary leakage whilst having intercourse is enough for some to abstain from sexual encounters.

The emotional distress someone experiences when they are diagnosed and living with MS can feel like a crisis. This is exhausting for people who have to deal with many different challenges at the same time, affecting how they feel about themselves (Mathews, 2009). Rutter (2000) suggests living with MS can alter an individual's sense of identity.

If someone's body image is damaged, it can lead to grieving for their former healthy self, as described by Kübler-Ross (1969).

3 MS-related sexual dysfunction

The attitude of others can be significant and some people with MS find it challenging to begin new relationships. Ward-Abel and Hall (2012) describe how people with MS are embarrassed by how the disease has changed them. They lose confidence and withdraw from society. A satisfactory body image often comes from other people's approval (Price, 2000; Gagliardi, 2003). Pain, exhaustion, loss of physical control, such as sensory, motor or neurological ability, all influence someone's idea of how they look. A diminished sense of wellbeing damages body image even further (DeFrank et al, 2007).

[Click here for references](#)

LINKS

Sexuality in Later Life [www.nia.nih.gov](http://www.nia.nih.gov)

Living with Multiple Sclerosis-Body Image [You Tube](#)

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“Sexual expression is something people can take for granted, and only appreciate its impact on quality of life when it has been taken away.”

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## 4 Why we should ask about sexual health and wellbeing

HCPs often feel inadequate, ill equipped and uncomfortable asking questions about sex. HCPs can be biased in thinking people are too disabled or too old to be sexually active. Some HCPs believe that sexuality and sexual dysfunction does not fall within their role. So problems associated with a patient's sexual activity are very likely to be overlooked by professionals (RCN, 2000; Rubin, 2005).

Added to this, only 10% of patients with a sexual difficulty are confident enough to ask their GP for help.

Some HCPs feel they do not have time to ask about sexuality and sexual dysfunction. They think the patient would rather concentrate on the physical aspects of their disease. Some argue they wouldn't want to be asked about sexual difficulties if they were a patient. However, sexual dysfunction is one of the most distressing aspects of MS for an individual and his or her partner (Zorzon et al, 1999). Koch et al (2002) establish that women with MS are interested in their sexuality regardless of their disability and regard it as a normal part of everyday life. Studies consistently show people want to be asked about this aspect of their life.

“Some HCPs believe that sexuality and sexual dysfunction does not fall within their role. So problems associated with a patient's sexual activity are very likely to be overlooked.”



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“Sexuality needs to be at the core of nurse education if nurses are to be truly holistic in their care. The neglect of sexuality and intimacy can be devastating.”

## Marital breakdown

Sexual dysfunction must be addressed early. A study by McCabe (1996) showed one third of couples experienced marital breakdown because of added pressures on their relationship. Individuals who are single have concerns about meeting someone new.

## A legitimate aspect of care

Sexuality remains a taboo subject in medical and nursing professions. But the close relationship MS nurses have with their patients means they are ideally placed to help explore sexuality and sexual wellbeing. The RCN (2000) aims to legitimise sexuality as a core aspect of nursing care, enabling nurses to recognise that sexuality and sexual health is an appropriate and justifiable area of nursing. Furthermore, The World Association for Sexual Health (WAS, 2014) advocates all individuals have the right to sexual healthcare and information and highlights the need to raise awareness of disabled people's rights to sexual healthcare.

Addressing sexuality with patients is challenging, as traditional teaching and education has not focused on the importance of sexuality and intimacy.

Sexuality needs to be at the core of nurse education if nurses are to be truly holistic in their care. The neglect of sexuality and intimacy can be devastating. HCPs can have a positive impact on patients by addressing and understanding the problems because this means they will be managed and treated.

## Who'll go first?

Research demonstrates patients want nurses to discuss sexuality. Most find it difficult to approach HCPs and hope the HCP will broach the subject first.

Holistic care is fundamental to nursing and the Royal College of Nursing (RCN, 2007) has promoted the 'equalities champion' role to help address inequalities. MS nurses can help overcome socially constructed barriers, stigmatisation and oppression by educating other HCPs in the importance of addressing sexuality and MS.

Only 10% of patients with a sexual difficulty are confident enough to ask their GP for help and many would prefer to talk to a nurse. On average, men will take a minimum of two years to discuss their sexual dysfunction with a health professional (Evans, 2010). The awareness of sexual function on quality of life is now emerging as an indicator of good patient management (Bronner et al, 2010).

It is also essential that as HCPs, we understand our own views on sexuality and sexual function. These attitudes influence whether we assess the patient and the management strategies that we discuss.

A nurse is ideally placed to act as an advocate for patients by incorporating sexuality in assessments and championing patients' rights.

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“Young people with MS will probably want to develop their knowledge but may be anxious about asking such questions or vague when asked about sex, sexuality and intimacy.”

## MS and young people

MS is most likely to be first diagnosed in young people under the age of 30, when they are at their sexual peak.

In a worldwide survey of 4,600 people by the journal *MS in focus* in 2013, 40% (1,860) were diagnosed under the age of 30 and more specifically, 37% between the ages of 21 and 29.

The implications of these findings for HCPs are clear – nearly half of all new patients are likely to be sexually active, whether they are in stable relationships or single.

Even mild symptoms can affect a young person's body image and self-esteem – generating anxieties about their sexuality and fears about whether this chronic illness will lead to disability.

Young people diagnosed with MS may not have sexual knowledge or experience, they may find casual exchange about sexual matters with their HCP difficult (McCabe et al, 1996). Their family's presence at appointments may inhibit open communication. Young people with MS will probably want to develop their knowledge but may be anxious about asking such questions or vague when asked about sex, sexuality and intimacy. Despite a much more liberal attitude to sex, some young people may not want to discuss their intimate lives with family.

HCPs need to be particularly sensitive to young people's situations and let them know that sexuality can be discussed when the young person feels ready. The HCP carries an important responsibility to discuss sexual activity with young people and endorse their sexual needs.

An HCP can encourage them to express fears and difficulties, refer them to specialists and sources of information.

Among the key issues young people may need to discuss are when they disclose their diagnosis, how they discuss the illness in existing relationships, how they put MS in context so it does not define who they are. Some may want advice on online dating or social networking sites run by MS organisations.

A young person may also be concerned about pregnancy, fertility and whether they will be able to look after a child in future.

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## Sexual response and ageing

There is a commonly held belief that older people, particularly women, are not sexually attractive, that older people do not have sex and it is less important as they age. But we now live longer and it is becoming increasingly difficult to establish what 'older' actually means. What age range does this term represent?

A survey by the American Association of Retired Persons (1999) asked 'does sex become less important to people as they age?' In response, 39% of men and 37% of women agreed. But when the question was, 'is sex only for younger people?' only 2% of men and 5% of women agreed.

Ageist beliefs on sexual behaviour are common amongst HCPs and this prevents them asking about sexual difficulties. It is essential that HCPs actively enquire about sexual dysfunction in the older MS patient and are conscious of stereotypical attitudes. Garrett (2014) recommends gentle and confident open-ended questioning. The HCP should understand the knowledge and beliefs of an older person and be aware they may use different language to express sexual difficulties.

“Ageist beliefs on sexual behaviour are common amongst HCPs.”

[Click here for references](#)

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“Sexuality is what makes us who and what we are. It is essential, however, that sexuality is not just about the sexual act or sexual activity; it is so much more than this, whether in health or illness.”

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## 5 How to take a sexual history

Taking a sexual history can worry HCPs. They may be embarrassed about asking intimate questions or believe the patient will be uncomfortable. They can feel they do not know the patient well enough, or don't have time to discuss this complex issue. They fear the patient may ask them something they know little about.

HCPs are more likely to tackle sexual health and wellbeing if the patient instigates the conversation. But research shows patients are embarrassed too, that they lack the language or confidence to discuss their sexual difficulties and are waiting for the HCP to initiate the conversation.

If we, as HCPs, worry about approaching the subject, is it fair to expect the patient to?

**“In a welcoming, comfortable and confidential environment you are more likely to have an effective two-way conversation where the patient feels they can discuss sensitive issues.”**

### Confidentiality

It is essential the patient feels assured that any information they disclose is in strict confidence and not released without permission. If the patient is not confident about these safeguards, they will be reluctant to tell their complete story, which will make planning and treatment ineffective.

All National Health Service (NHS) employees are bound by the Caldicott Principles for confidentiality (1997). They are also bound by their health professional council – e.g. Nursing & Midwifery Council (2008), which stresses the importance of confidentiality. General health confidentiality in the UK is a common law duty. It is essential to identify certain situations when confidentiality cannot be maintained, such as ‘when it is in the patient’s or public’s interest’. Unfortunately, this is vague but will include child protection, or cases where another individual is placed at risk of abuse.

Remind yourself of your professional code of conduct on sexual consultations.

### Safe environment

Ensure you have enough time and the right venue.

In a welcoming, comfortable and confidential environment you are more likely to have an effective two-way conversation where the patient feels they can discuss sensitive issues.

Put a sign on the door so you are not disturbed during the consultation.

Explain to the patient that discussing sexuality is part of a professional consultation and important in their overall management. Be relaxed, friendly and explain that the questions you ask are designed to help.

Students should be present only with the patient’s consent.

#### LINKS

Regulation in practice [www.nmc-uk.org](http://www.nmc-uk.org)

UK national guidelines [www.bashh.org](http://www.bashh.org)

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## Resources

Explore the specialist sexual services available locally to refer on if necessary – you will need to have mapped these out before you see a patient (see Section 14 for examples of the more general resources).

Start a resource folder on your computer or on your desk. Gather books and leaflets that you could give out to the patient at the appointment and take these with you to clinic.

Collect website addresses.

Consider whether you wish to use a formal sexual assessment tool (see Section 6).



## Beginning the dialogue

Most patients prefer to see the MS nurse first on their own.

Greet the patient warmly.

Ensure they are as relaxed as possible – look for physical signs of nervousness and embarrassment, such as a flushed neck, nervous hand movements or lack of eye contact.

Start with a social history to find out about their family, friends, work, to give useful background information and help to put medical problems into perspective.

## Obtain a baseline history

Do not assume your patient is heterosexual. This can alienate a lesbian, gay or bisexual patient and result in misinterpretation of symptoms and misdiagnosis. You should cover:

- Sexual problems prior to MS
- Genital surgery
- For women, their obstetric, gynaecological and menstrual history
- Concomitant medical conditions such as diabetes, cardiovascular disease, cancer, depression
- Drugs: prescribed and recreational
- Work and social stresses
- Whether children are still at home
- Evaluate the person's sexual knowledge – do they have any misconceptions or misunderstandings?

## Techniques for identifying patients' problems

Patients often have difficulty with this conversation. Pick up clues and clarify them.

Try and find out precisely what the patient is talking about. E.g. 'I think I am impotent' can often mean 'I have premature ejaculation'.

Asking open questions such as 'tell me what problems you are having' allows patients to explain in their own words how they are experiencing the difficulty and allows you to record:

- The severity of symptoms and their duration
- The relationship, its duration, the age and gender of a partner, details of any possible cultural or religious differences
- Number and gender of current sexual partners
- If multiple current partners, is the problem restricted to one partner?
- Previous sexual partners and any problems experienced with them
- Does the partner have a sexual difficulty?
- Type of intercourse – vaginal, oral or anal
- History of sexual abuse and assault
- Forms of contraception
- Previous sexually transmitted infections and treatments

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## Taking the dialogue further

The 'Sexual Respect Toolkit' suggests opening lines to begin discussing the topic of sex:

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

- Establish how much of the consultation to record in notes, letters, etc.
- Avoid medical terms, as the patient may not be sure what you mean.
- Do not be judgemental as this creates barriers. An embarrassed and anxious adolescent can appear confrontational and an older or disabled person can feel ashamed having to ask for advice.
- Respect patients' silence as during that time they may be formulating an answer.
- Postural echo: this technique will tell you when patients are fully at ease. If they are, they will sit in an exact mirror image of you. It can also be used to make someone feel easier, if you adopt their position in reverse.
- Repeating a patient's last few words or sentences is a valuable technique to persuade the patient to expand what he or she is trying to say; it can be a very powerful way of extracting information.
- Clarify the issues – ask questions and pick up clues.
- Provide sex education as needed.
- Assess if sexual problems are primary, secondary or tertiary (see Section 3).
- Establish the patient's goals.

- Is the patient willing and ready to change their thoughts, and behaviour? Is the partner?
- Come up with an action plan and be aware that there may be a counselling element to this discussion.

## Agreeing an action plan

An action plan should be discussed and agreed by the patient. For example:

- If spasms make sex difficult due to tight adductors, then the patient could try alternative positions.
- If fatigue is an issue, suggest trying an alternative time of day.
- Agree a review date.

If, by the end of the consultation, you feel the patient requires specialist management, refer on.

## Conclusion

A good history, carefully taken, can save a lot of repetitive questioning and missed diagnoses, while enabling the patient to be more comfortable about discussing a potentially embarrassing issue.

“A good history, carefully taken, can save a lot of repetitive questioning and missed diagnoses, while enabling the patient to be more comfortable about discussing a potentially embarrassing issue.”

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## General medical and neurological factors that impact on sexual functioning

### Psychosocial

- Depression
- Work related stress
- Financial difficulties
- Lack of a partner
- Feelings of guilt
- Altered body image and lowered self esteem
- Relationship problems, tension and incompatibility with partner
- Libido
- Lack of intimacy
- Performance anxiety
- Partner's health problems
- Lack of sexual knowledge – some may not understand how the sexual organs respond or don't use appropriate arousal techniques
- Previous sexual trauma or abuse
- Restrictive childhood and up-bringing.

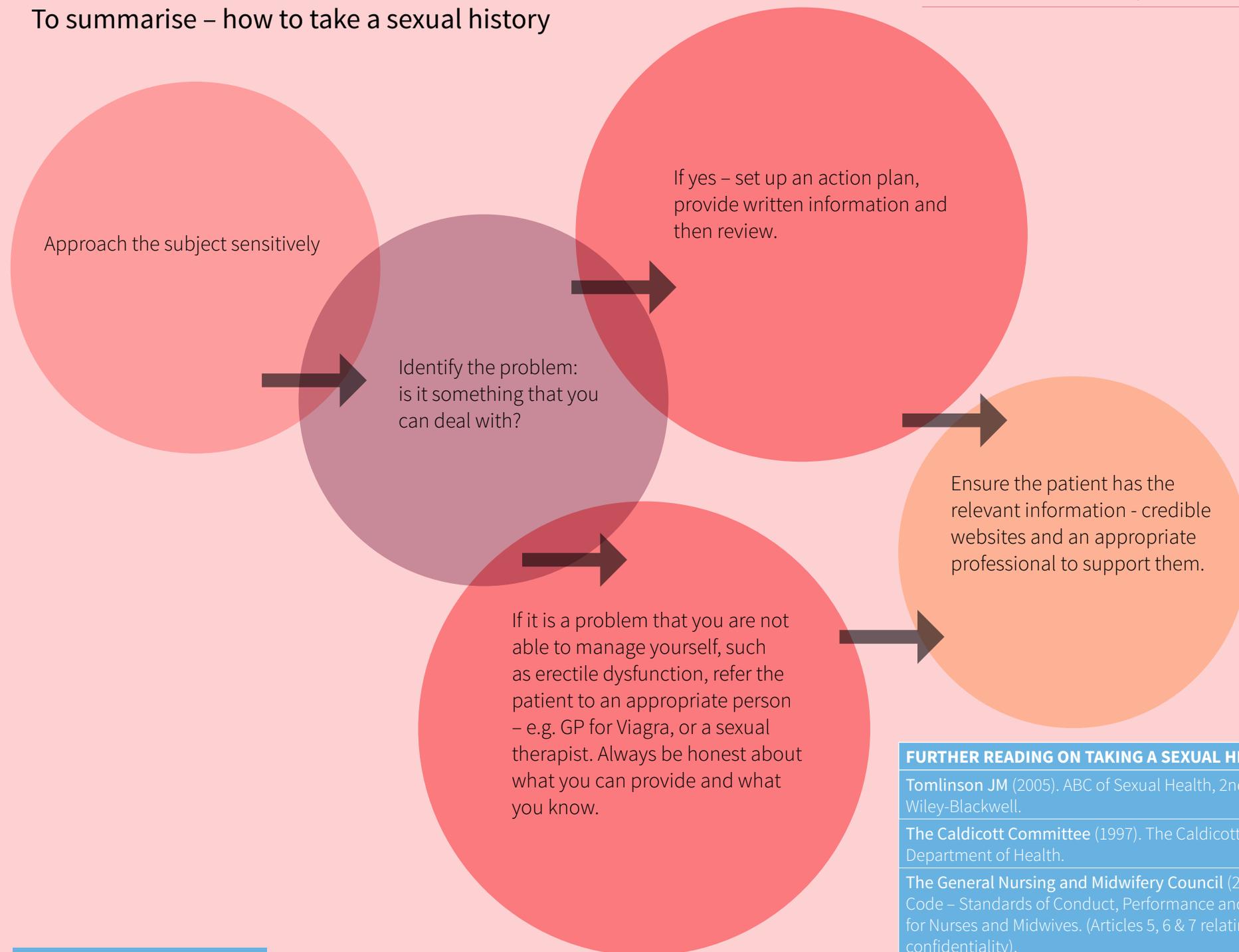
### Physical

- Spinal cord injuries
- Conditions that affect the ability to participate in 'normal' sexual activity, such as the spasticity caused by cerebral palsy
- An enlarged prostate gland
- Diabetes
- Neurological conditions such as Parkinson's disease or MS
- Fatigue
- Pain and sensory problems
- Some drugs such as alcohol, nicotine, narcotics, stimulants, antihypertensives ([click here](#) for a more comprehensive list)
- Endocrine disorders of the thyroid, pituitary, or adrenal glands
- Heart and vascular disease
- Kidney or liver failure
- Disorders of the genitalia and urinary system, such as endometriosis, cystitis, vaginal dryness or vaginitis
- Surgical removal of the uterus or of a breast may contribute psychologically to sexual dysfunction if a woman feels her self-image has been damaged
- Hormonal deficiencies (low testosterone, oestrogen, or androgens)
- Ageing; in males this is associated with declining testosterone levels. In females, with lowering oestrogen.

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## To summarise – how to take a sexual history



## FURTHER READING ON TAKING A SEXUAL HISTORY

Tomlinson JM (2005). ABC of Sexual Health, 2nd Ed. Oxford: Wiley-Blackwell.

The Caldicott Committee (1997). The Caldicott Report. Department of Health.

The General Nursing and Midwifery Council (2008). The Code – Standards of Conduct, Performance and Ethics for Nurses and Midwives. (Articles 5, 6 & 7 relating to confidentiality).

[Click here for references](#)

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“Sexual drive is identified as a basic human need at the lowest physiological level and as such must be satisfied before higher needs can emerge.”

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## 6 Assessing someone with MS-related sexual difficulties

The approach a nurse takes when taking a sexual history also applies when assessing a patient's sexual difficulties.

Specific questions provide the patient with permission to discuss their problems (Woods, 1987):

- In what ways (if any) has your MS affected the way you see yourself as a husband/wife/partner/father/mother/friend?
- In what ways (if any) has your MS affected how you see yourself?
- Many people who have MS find they have some difficulties with their abilities to be sexual. Is this something you experience? If so, it is okay to talk about?
- In what ways would you like things to be different?

White and Heath (2005) suggest two ways of approaching a conversation about sex:

1. Explore with the patient the direct impact of illness or its treatments on the expression of sexuality or intimate relationships.
2. What is the relationship context, such as who is around for you? Who are you close to? Who is important in your life?

There are a number of specific sexual assessments which can be helpful. They are listed below.

- **Multiple Sclerosis Intimacy and Sexuality Questionnaire 19**
- **International Index for Erectile Function**
- **Female Sexual Function Index.** A 19-question, six-domain questionnaire that assesses aspects of female sexual function: desire, subjective arousal, lubrication, orgasm, satisfaction and pain. It covers a broad range of categories relating to female sexual health, although it is difficult to score. A cutoff score (26.55) can be used to delineate women at high risk for sexual dysfunction, making this instrument much more efficient to interpret.
- **The Arizona Sexual Experiences Scale (ASEX)** quantifies sex drive, arousal, vaginal lubrication/penile erection, ability to reach orgasm, and satisfaction from orgasm. Possible total scores range from five to 30, with the higher scores indicating more sexual dysfunction.
- **The Female Sexual Distress Score** (Derogatis et al, 2008). A 13-question survey.
- **The UK Neurological Disability Scale.** Not specifically a sexual assessment but if you want to ask about sexual difficulties as part of 'routine' questioning, this is ideal.

- **Recognition model**
- **P-LI-SS-IT and Ex-P-LI-SS-IT**
- **BETTER**

The level of intervention required may vary, depending on the HCP's own values, beliefs, knowledge, confidence and comfort levels. It is essential that these issues be fully explored, as personal attitudes could have significant affect upon the efficacy of interventions.

Equally, HCPs need relevant training, clinical supervision and support in providing holistic care.

Springer et al (2001) recommends following a specific care plan in addition to applying the P-LI-SS-IT model (Annon, 1976) to assist individuals who have difficulty discussing sexual issues.

LINKS

The Arizona Sexual Experience Scale  
[www.saadshakird.com](http://www.saadshakird.com)

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### Create the right conditions for an assessment

- Provide a non-judgemental atmosphere for discussion, to enable open expression of feelings about perceived changes in sexuality.
- Ensure privacy to show you respect and acknowledge the sensitivity of the individual's concerns.
- Ask permission before moving on to another area of assessment.
- Begin with general questions before moving on to specifics.
- Use neutral language to allow individuals to express concerns without fear of being judged.
- Normalise and validate the discussion, to provide affirmation and ensure individuals do not feel alone or unusual for expressing sexual concerns.
- Provide reassurance based on facts, to avoid instilling false hopes.

### The need for specific assessment tools:

Lewis and Bor (1994) suggest that including a sexual history within the initial assessment process provides permission and opens up an opportunity for discussion. Although individuals may not be experiencing problems, drawing up a sexual history acknowledges there may be sexual problems associated with MS. This may dispel embarrassment and encourage individuals to discuss issues in the future. If concerns over sexual activity are not addressed after initial diagnosis and as part of a general holistic assessment, it is probable they never will be. Therefore, sexuality should be included within assessment processes from diagnosis onwards (Springer et al, 2001).

Following initial assessment and when sexual problems are identified, the patient may need a more specific assessment. There are various assessment frameworks (Burgess, 2002; Foley et al, 2013; Foley et al, 2000; Springer et al, 2001). Considering the impact of MS on sexuality – and the classifications, which encompass primary, secondary and tertiary causes – is a useful model for a holistic approach to care (Foley and Sanders, 1997a; Foley and Sanders, 1997b). The Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ) is a self-reported questionnaire, which provides useful screening to help individuals and HCPs identify difficulties. It may also help encourage personal responsibility and self-management.

Self-reported questionnaires are very reliable in assessing sexual function and satisfaction.

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## Recognition Model

The Recognition Model (Couldrick, 2010) expands on the P-LI-SS-IT model for use with people with disabilities. It takes a team approach, to protect and support the sexual health of individuals with disabilities, using all team members' skills and knowledge regardless of role. It encourages permission-giving strategies to allow affirmation of the individual's questions and response.

It clarifies professional roles, which is useful when working in multidisciplinary teams, and indicates how people with MS might be encouraged to talk about their concerns, explore cultural beliefs, attitudes and awareness.

### Key advantages

- Recognises the patient as sexual being.
- Provides sensitive strategies.
- Explores concerns.
- Addresses issues that fit within the team's expertise and boundaries.
- Refers on when necessary and appropriate.

### LINKS

Recognition model [www.mstrust.org.uk](http://www.mstrust.org.uk)

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## P-LI-SS-IT and Ex-PL-SS-IT Models

**P**

Permission  
for the client to discuss  
their sexual difficulties  
and problems

**LI**

Limited  
Information  
share factual or  
evidence-based  
knowledge

**SS**

Specific  
Suggestions  
for action

**IT**

Intensive Therapy  
if agreed it's needed.

The P-LI-SS-IT Model was developed by Jack Annon (1976) and is an acronym of Permission, Limited Information, Specific Suggestions and Intensive Therapy. He said:

“Many sexual dysfunctions of longstanding concern need only understanding and a common sense approach for their resolution.”

“Many sexual dysfunctions of longstanding concern need only understanding and a common sense approach for their resolution.”

It was developed to help discussion of sexuality and sexual dysfunction in clinical practice. It can help evaluate how much intervention individuals need and offers HCPs a series of practice levels, based on personal experience, knowledge and comfort in discussing sexuality.

The Ex-P-LI-SS-IT Model is an extended version.

It encompasses permission-giving as a core element of each stage in the original linear P-LI-SS-IT Model (Taylor and Davis, 2007; Taylor and Davis, 2006; Davis and Taylor, 2006). Male HCPs who might have increased concerns about appearing non-professional when trespassing into a sensitive-taboo area may feel more comfortable using the Ex-P-LI-SS-IT model.

The P-LI-SS-IT model is a form of ‘stepped’ approach to sexual dysfunction. Annon (1976) feels that fewer people need increasing levels of care. Tan et al (2002) reports that 80–90% of patients need no more than information and brief sexual advice. For an overview of this model, take a look at this: [www.youtube.com](http://www.youtube.com)

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## P Permission

Annon (1976) emphasises the importance of listening to the patient without jumping to conclusions. He feels it is important to normalise behaviours to reduce anxiety, guilt and shame. The only treatment some people may need is reassurance that they can have sexual intercourse or relationships despite (for example) spasticity. But the patient may need to adapt their position to make this possible.

### Example of how to give permission:

**Start with:** “I am going through some general questions regarding your MS, some of them are quite personal, are you happy for me to ask?”

**Routine questioning:** “Now we have discussed your fatigue, I would like to ask you questions about how MS has affected you sexually – is that OK with you?”

**Generalising/normalising:** “After being diagnosed with MS, most women say they have difficulties resuming intimate relationships. Has this been an issue for you?” then “How does this make you feel?”

**Using statistics:** “Over 70% of men with MS say they have some difficulties with sexual relationships. Is this an issue for you?”

**Other open-ended questions:** “How are things at home?”

“I am going through some general questions regarding your MS, some of them are quite personal, are you happy for me to ask?”

## L Limited Information

Sexual knowledge is often built on myths and incorrect information. The idea of ‘limited information’ is to replace this with factual or evidence-based knowledge. The information focuses on the patient’s area of concern. For many, the information they receive provides great relief and no further help is needed.

The kind of information that might be useful includes the side effects of medication, family planning, and education on sex and intimacy.

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## SS Specific Suggestions

These are direct attempts to help the patient change his or her behaviour in order to reach a sexual goal, but these suggestions can only be given after an assessment of the sexual difficulties the individual is experiencing.

This may include strategies to help erectile dysfunction or loss of libido, or more specifically, reduced sensation around the perineal area affecting climax. In this instance, if sex toys have not been helpful, a psychosexual counsellor could help with more specialised therapy, such as sensate focusing (using touch to learn how to give and receive pleasure rather than sexual intercourse).

## IT Intensive Therapy

The MS HCP needs to be self-aware and recognise when issues discussed are either beyond their expertise or beyond the scope of their professional code of practice. In either of these instances, sometimes the patient will need further professional help.

### Key advantages of P-LI-SS-IT tool

Enables the professional to ask and discuss the subject in a sequential structured format.

### Disadvantages

Some say it is now out of date and no longer reflects UK culture and the evolving interprofessional relationship between patient and HCP.

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## BETTER Model

Cohen and Hughes' (2004) BETTER Model to assess sexuality was developed within mental health nursing in Australia.

**B** Bring up...  
Bring up sexuality and sexual functioning.

“Some women have questions or concerns about their sexual functioning when they have MS. We try to address these concerns as they arise, so please feel free to ask me anything.”

**E** Explain...  
Explain that sexuality is integral to quality of life and important to discuss.

“Some women find that living with MS can change their interest in and arousal during sex. This can have a big impact on their life. Is this something you and your partner have talked about?”

**T** Tell...  
Tell patients about available resources and help them if the information they need isn't immediately available.

“I'm not sure of the answer to that, but I have a colleague who has a lot of experience in this area. With your permission, I'll ask them about this and get back to you when I see you next week.”

**T** Timing...  
Timing is crucial – discussions should be encouraged as the patient/partner desires.

“It may be that this isn't the right time for you to talk about this. You may not feel like thinking about or resuming sexual activity yet, but you can always call me to ask any questions you or your partner may have. I'll also give you some written information that you can read when you feel ready.”

**E** Educate...  
Educate the patient/partner about any expected or potential changes in sexuality or sexual functioning.

“Some women find that they have problems with vaginal dryness. This can make sex painful and can reduce desire for intercourse. Have you considered a lubricant? Some women find the Durex range helpful. There are others that are silicone-based.”

**R** Record...  
Record important aspects of any discussions, assessments, interventions and/or outcomes in the patient's record.

“The need for vaginal lubrication was discussed with the patient. Some strategies to accomplish this were discussed.”

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## Multiple Sclerosis Intimacy and Sexuality Questionnaire 19

Validated in two previous studies (Sanders et al, 2000; Foley et al, 2007), this is a really helpful questionnaire composed of 19 questions that ask the patient to rate how various symptoms of their MS have interfered with their sexual satisfaction or activity over the last six months.

Asking patients to complete this questionnaire gives a good idea of the extent of their problems (as the response is rated on a scale of 1–5) and the relative contribution of primary, secondary and tertiary sexual dysfunction.

### MSISQ: Primary Sexual Dysfunction five items, including:

- 1 Lack of sexual interest/desire
- 2 Decreased genital sensations/genital numbness
- 3 Takes too long to orgasm/climax
- 4 Less intense or pleasurable orgasms/climaxes
- 5 Inadequate vaginal lubrication (women)/ Difficulty getting/keeping satisfactory erection (men)

### MSISQ: Secondary Sexual Dysfunction five items, including:

- 1 Muscle tightness/spasticity
- 2 Bladder/urinary problems
- 3 Bowel problems
- 4 Tremors in hands or body
- 5 Pain, burning, or discomfort in body

### MSISQ: Tertiary Sexual Dysfunction five items, including:

- 1 Body image/attractiveness concerns
- 2 Feeling less feminine/masculine
- 3 Fear of being rejected sexually because of MS
- 4 Feeling less confident about sexuality due to MS
- 5 Worries about sexually satisfying partner

#### LINK

Sexuality in MS: a practical guide for nurses  
[www.academia.edu](http://www.academia.edu)

Find a copy of the MSISQ [www.med-iq.com](http://www.med-iq.com)

#### OTHER USEFUL SEXUALITY ASSESSMENT TOOLS

Sexual Health Inventory for men  
International Index for Erectile Function (Rosen et al, 1997. *Urology*, 49, 822-830)  
Female Sexual Function Index (Rosen et al, 2000. *Journal of Sex Marital Ther*, 26, 191-208)

[Click here for references](#)

## The UK Neurological Disability Scale

This is a basic structured questionnaire covering symptoms and sexual function.

### Key advantages

Covers 12 areas considered important by neurologists, providing a useful general background.

Captures many aspects of everyday life, including sexuality and sexual function.

May be useful in opening up further discussion.

## The Sexual Respect Toolkit

Online toolkit for GPs and other health and social care professionals to feel more comfortable initiating discussions about sex.

Resources include information handouts, discussions, posters and training film.

#### LINK

The sexual respect toolkit  
[www.sexualrespect.com](http://www.sexualrespect.com)

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“Questions concerning sexuality should be recognised as a legitimate part of the patient assessment” (NICE, 2014)

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## 7 Supporting the partner

If partners are unaware of the sexual problems experienced by a patient, they may feel confused and misinterpret this as a rejection or failure on their part. They may feel resentful or hurt. It is better to be honest and confront the situation together so that a plan of action can be agreed (MS Trust).

It is important to recognise and provide support for partners. This may include advice on new sexual relationships and the effects this may have on their existing relationship, as well as addressing changes in an established relationship as a result of someone's condition.

Studies such as Kreuter et al (1994) on sexual adjustment after spinal cord injuries found: "emotional factors such as honesty, trust, closeness, mutual respect, communication, caring and appreciation were reported to be important factors in maintaining a positive and satisfying sexual relationship".

"It is almost impossible to have good sex without good communication" (Kaufman et al, 2003). It is important to encourage couples to be open, as one partner may be confused about what the other needs. Encouraging couples to be open about changes in their sex life can help them overcome embarrassment and can increase enjoyment. "Disability is sometimes used as an excuse not to talk about sex, as the non-disabled partner may feel they may be hurting the other partner by bringing it up" (Kaufman et al, 2003).

Some people may lose interest in sex, due to concerns about hurting their partner; they may be adjusting to a new diagnosis.

But do not assume that MS is the only cause of sexual dysfunction. There are other factors, such as cardiovascular disease, vascular risk factors, diabetes mellitus, hypertension, smoking, alcoholism, recreational drug use, or medication, as well as psychological and emotional issues.

**“Emotional factors such as honesty, trust, closeness, mutual respect, communication, caring and appreciation were reported to be important factors in maintaining a positive and satisfying sexual relationship.”**



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“It is almost impossible to have good sex without good communication.”



Kessler (2009) recognised that “the patient’s attitude towards secondary sexual orientation and quality of the relationship with the spouse or partner should be addressed and that assessment of not only the patient’s but also the partner’s needs and expectations is equally important and the effect of sexual dysfunction on a couple should be considered and is beneficial to engage the partner as well”.



One way of opening communication may be to ask both partners to complete the MS (MSISQ-19) questionnaire to establish whether they identify similar issues or concerns about their sex life. Partners should be encouraged to attend review appointments, or be offered a separate appointment.



Reassure couples that it’s OK to ask for help, that there’s no need for them to feel embarrassed or isolated. It’s important they realise that many people who are not dealing with a medical condition experience changes in their sexual function at some time during their lives, whether because of stress, a change in relationship, a new relationship, or age. Research on sexual health issues is scarce, especially among people with a disease or impairment. But the prevalence of sexual difficulties among the general population is thought to be high, although people are often reticent about seeking help, even from primary care professionals (Kedde et al, 2012).

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It's also important to manage a couple's expectations. For example, it is not the case that everyone should climax. Education and information is vital so couples can realise that relationships change. Physical intimacy, such as hugging and stroking, is important in any relationship, especially when full sexual contact is not possible. Emotional intimacy is also vital – sharing, spending time together and being there for each other. Point out that communication takes place in various forms like using body language, facial expressions, moaning, moving, laughing or crying – all these are ways of making our feelings known.

Reassure couples that it's OK to experiment with different positions to achieve penetration. Creating a better understanding of the difficulties a partner may be experiencing means that you can make suggestions that help couples rebuild an active/alternative sex life (MS Trust).

*“Partners should be encouraged to attend review appointments or be offered a separate appointment.”*



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Sextherapist Gila Bronner says partners need different types of time together (Bronner et al, 2010):

- Couple time – socialising together, dating
- Intimate time – talking, sharing, listening, loving, caring, supporting each other emotionally and physically
- Sexual time – relaxing, touching as well as non-sexual touching
- Personal time – erotic touching, thinking, sexual excitement, activity and satisfaction

Talk to the patient about how he or she can develop this aspect of their life.

Bronner lists a person's rights to a good quality sex life:

- The right to love and be loved
- The right to touch and be touched
- The right to share intimacy
- The right to be a sexual human being

Remind couples about the importance of maintaining a good sense of humour, as sex is fun.

HCPs cannot profess to have specialist knowledge in all aspects of patients' care. However, by carrying out holistic assessments and seeing people for regular reviews, it gives us the opportunity to build a rapport with couples.

"Every person (or couple) with persisting sexual dysfunction should be offered the opportunity to see a specialist (with particular expertise in sexual problems associated with neurological disease) and offered, as appropriate, advice on lubricants and the use of sexual aids, and other advice to ameliorate their sexual dysfunction." (NICE, 2003)

**“Remind couples about the importance of maintaining a good sense of humour, as sex is fun.”**



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## Intimacy

The MS nurse/practitioner who is trying to engage in a discussion about intimacy with a patient or couple needs to be aware that these issues are extremely sensitive and normally thought of as private. They demand a great deal of careful questioning to seek permission to raise and explore the subject.

No longer being able to express love and closeness in a physically intimate way can be a source of great regret, sadness and pain. This may lead a person or couple with MS to bravely seek solutions or improvements.

However, some couples will be resigned to the loss. The embarrassment of opening up to themselves, each other and HCPs can be too difficult and embarrassing.

**“No longer being able to express love and closeness in a physically intimate way can be a source of great regret, sadness and pain. This may lead a person or couple with MS to bravely seek solutions or improvements.”**

[Click here for references](#)

## Discussing sexual techniques with a couple

A trusting relationship between HCP, patient or couple is fundamental to an open discussion, without judgement .

Avoid the use of jargon and understand a person’s nicknames for anatomy and sexual techniques.

Completing a questionnaire – i.e. MSISQ-19 – may be easier for the patient or couple to do as homework rather than face-to-face. It can be discussed together at home and will give a score, which allows techniques and therapies to be evaluated.

A patient can write sexual preferences, dislikes or curiosity on post-it notes and leave them for the partner to read independently. Red for dislike or turn-off; orange for interested; green for ‘yes, please’.

In a group, not everyone will be comfortable with open discussion. Statements on flip-chart paper can be posted around a room. For example:

I feel sensual when...

I like it when...

I wish my partner would...

I am turned off by...

Give participants post-it notes to write comments on that can be anonymously attached to the flip-chart statement in the coffee break.

## 7 Supporting the partner

This identifies common themes which give individuals confidence that they are not alone.

Many people, including yourself, may not be fully aware of their sexual preferences. It is likely to be new territory for discussion and can stir up strong emotions. Having someone to debrief with afterwards can be helpful.

I feel sensual when...

I wish my partner would...

I am turned off by...

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## Case study: Lesley Betts

I developed MS 32 years ago when I was 20. It began quite dramatically with the loss of all feeling from the waist down, although strangely everything worked. I was still able to walk, albeit slowly and was told that it was the relapsing/remitting form of the disease and would come and go, but to go home and live as normal a life as possible. Looking back I realise that in the early days I treated having MS in a decidedly cavalier fashion, refusing to let it interfere with anything I wanted to do. I was still the same person until forced, every now and then, to go to ground and regroup as an attack occurred. Every time it happened I had a hefty dose of steroids and waited for it to subside, but began to notice that every attack left me just that little bit worse, pushing me, inexorably, towards the secondary progressive phase, which is where I am now.

“Mentally and emotionally the beast that is secondary progressive MS presents me with a far tougher job than I’d ever thought it would.”

## 7 Supporting the partner

And how does that affect me? Physically, it means full-time wheelchair use, a left arm and hand that refuse to work properly and the need to rely totally on a team of people who endeavour, on a daily basis, to make my life as straightforward as possible. I don’t like it, but that’s the easy part. Mentally and emotionally the beast that is secondary progressive MS presents me with a far tougher job than I’d ever thought it would. It is an insidious and frighteningly voracious adversary that constantly attempts to chip away at my confidence and overwhelm the very essence of me. The fact that I’m now incapable of doing things I used to love to do, such as baking and driving, are bad enough but not the end of the world. It is, instead, the steady but relentless loss of privacy and dignity that is the hardest to bear. Not being able to shower or dress myself and having to arrange my need to use the loo around someone else’s schedule is frustrating and, at times, upsetting. My overactive and maddeningly sensitive bladder has meant I now have a suprapubic catheter intrathecal Baclofen pump, to help control my violent muscle spasms.

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So, with all the equipment in my house to help me, plus my wheelchair, catheter and pump, can I be forgiven for sometimes losing sight of the person I once was? It's certainly hard at times to maintain a positive self-image with a tube sticking out of my stomach and a full leg-bag; to still feel that vibrant, sexy and passionate woman I like to think I was. When my partner, John, is called upon to see bits of me I've never seen myself, or perform duties that few men would ever be required to do, I worry. I worry every time he lifts me, turns me over in bed, never has a full night's sleep or gets me off the loo, that his role is changing from being my lover to that of my carer. However, communication is the key. We talk a lot about how MS affects him too. So much attention is focused on me because of the restrictions and requirements that go hand in glove with MS that I worry he will become overwhelmed by it and overlooked because of it. So honesty and communication are paramount. John sees MS as something we both have because what affects me, affects him and vice versa. When I ask him if it's all getting too much, that perhaps he'd like a break from having to deal with the MS, he says that I can't take a break from it, so why should he? His consideration and support means so much and it helps tremendously that he still finds me physically attractive and that the things he does for me he does not as my carer, but simply because he cares, that he loves and accepts me for who I am and helps me hold on to my self-confidence and determination on days when I

struggle to see the way forward. The limitations placed on us both by MS have also made us more considerate when it comes to sex and although it has robbed us of our spontaneity, with a little thought and application most things are achievable.

The MS, in a strange way, has brought us closer, because it's made us think outside the box. It makes us talk to each other, to say what we want or don't want, like or don't like, whether physically or emotionally and to appreciate each other, what we have together and the things we can do.

*“When I ask him if it's all getting too much, that perhaps he'd like a break from having to deal with the MS, he says that I can't take a break from it, so why should he?”*



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“Some medicines can affect libido and others can affect the ability to become aroused or achieve orgasm.”

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## 8 Medications that can affect sex

Some prescription medications and over-the-counter products can have an impact on sexual functioning. Some medicines can affect libido and others can affect the ability to become aroused or achieve orgasm. The risk is increased when an individual is taking multiple medications.

HCPs need to discuss the side effects with patients. Whilst it is unusual for drugs to be the sole cause of a sexual problem, they will certainly have an impact.

Patients on long-term medications may not be aware that their sexual problems are a result of their treatment.

### Libido

Lack of libido is more commonly experienced by women. Many have no problems achieving orgasm but their desire is low. The male sex drive can be influenced by reproductive hormones, particularly testosterone, which is required for sexual arousal. Medicines that reduce testosterone or block its effects are likely to reduce sex drive. Some literature states menopause affects libido but many women find it increases post-menopause. Medicines that cause drowsiness, lethargy, weight gain or confusion also have the potential to reduce libido.

### Arousal and erection

Some medicines have a direct impact on the blood vessels in the genitalia - the penis and clitoris. They can affect the transmission of nerve messages along the spinal cord. Selective serotonin re-uptake inhibitors (SSRIs) are well known for causing sexual difficulties, probably because they enhance the levels of serotonin, which seem to tighten the brain's built in controls of arousal and erection. Conversely, there are reports that SSRIs can lead to excessive sexual urges, so more research is needed into this area of care. Some anti-hypertensive agents can inhibit erections (penis or clitoris) and reduce arousal.

### Orgasm

A study of nearly 600 men and women treated with an SSRI, published in the *Journal of Sex and Marital Therapy*, found that roughly one in six patients reported new sexual problems. The main complaint was delayed or absent orgasms. Many patients also reported declines in desire. Overall, men were more likely than women to report sexual problems while on SSRIs.

### Ejaculation

The most widely prescribed centrally-acting agents that affect ejaculation are SSRI antidepressants.

Ejaculation is a complex reflex process that involves the activation of alpha receptors. Medicines that block alpha receptors can interfere with ejaculation.

During ejaculation, increased alpha receptor activation closes the bladder neck, facilitating the normal flow of semen out of the penis.

If this mechanism is disrupted, it results in retrograde ejaculation, with semen flowing from the urethra into the bladder.

Various chemicals in the brain are also involved in orgasm and ejaculation and medicines that affect these chemicals can cause disturbances.

### Vaginal dryness

A woman will naturally lubricate her vaginal walls with a layer of moisture. When she is sexually aroused the amount of fluids increases.

Dryness can be caused by hormonal changes, such as menopause, stress and certain medications including: anti-histamines, cold treatments, SSRIs and various cancer treatments.

#### LINKS

Sex and medications [www.netdoctor.co.uk](http://www.netdoctor.co.uk)

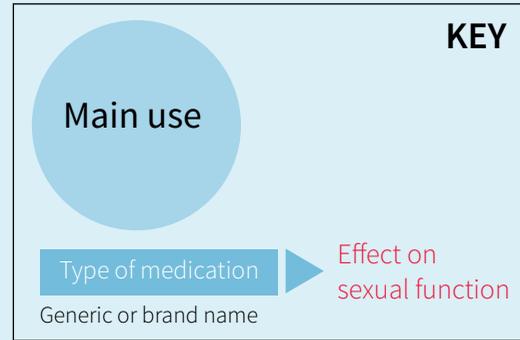
Factors affecting sex [www.inkling.com](http://www.inkling.com)

**MS, SEX, SEXUALITY and INTIMACY**

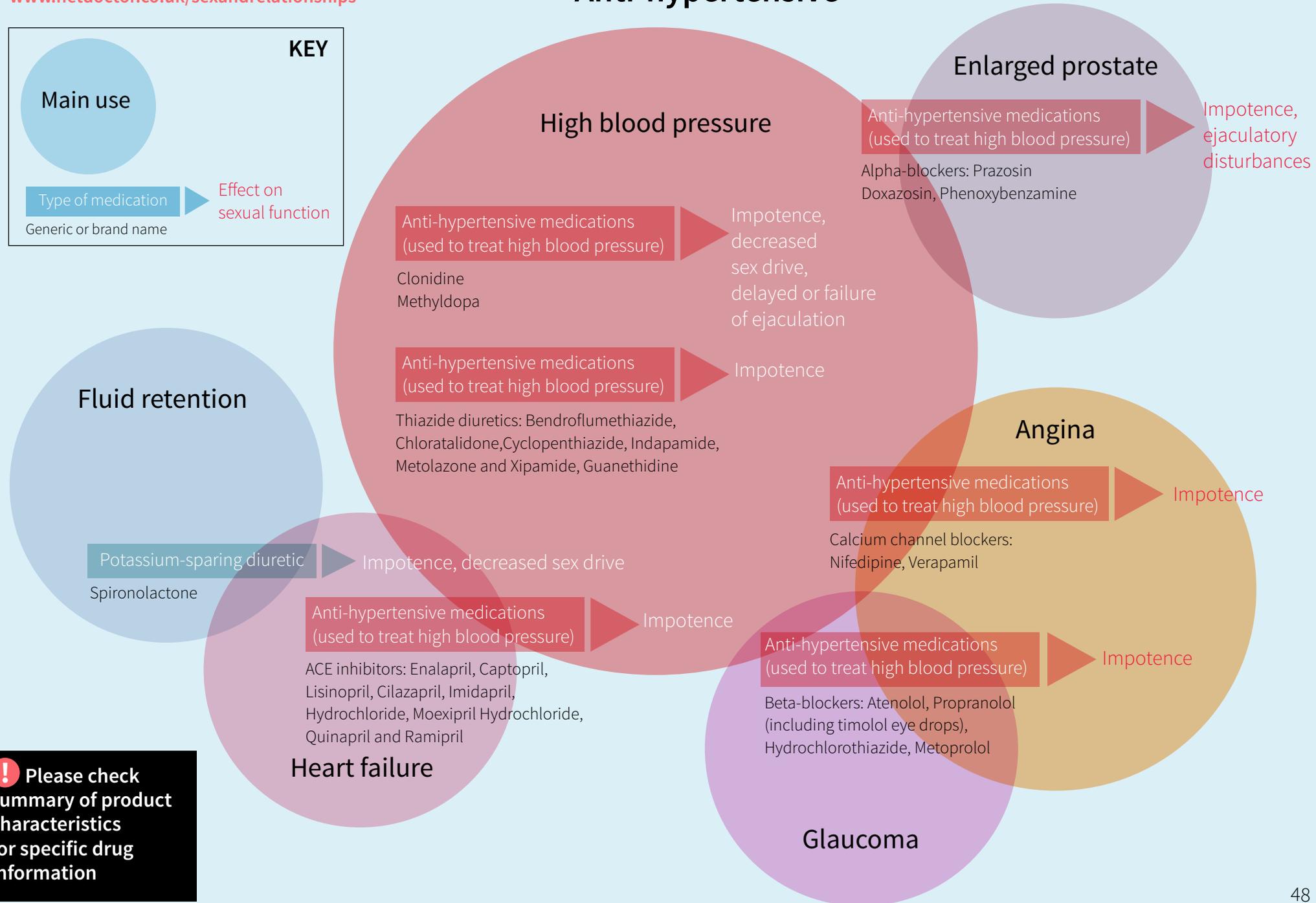
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Adapted from Dr John Dean  
 'Are your medicines disrupting your sex life?'  
[www.netdoctor.co.uk/sexandrelationships](http://www.netdoctor.co.uk/sexandrelationships)



**Anti-hypertensive**

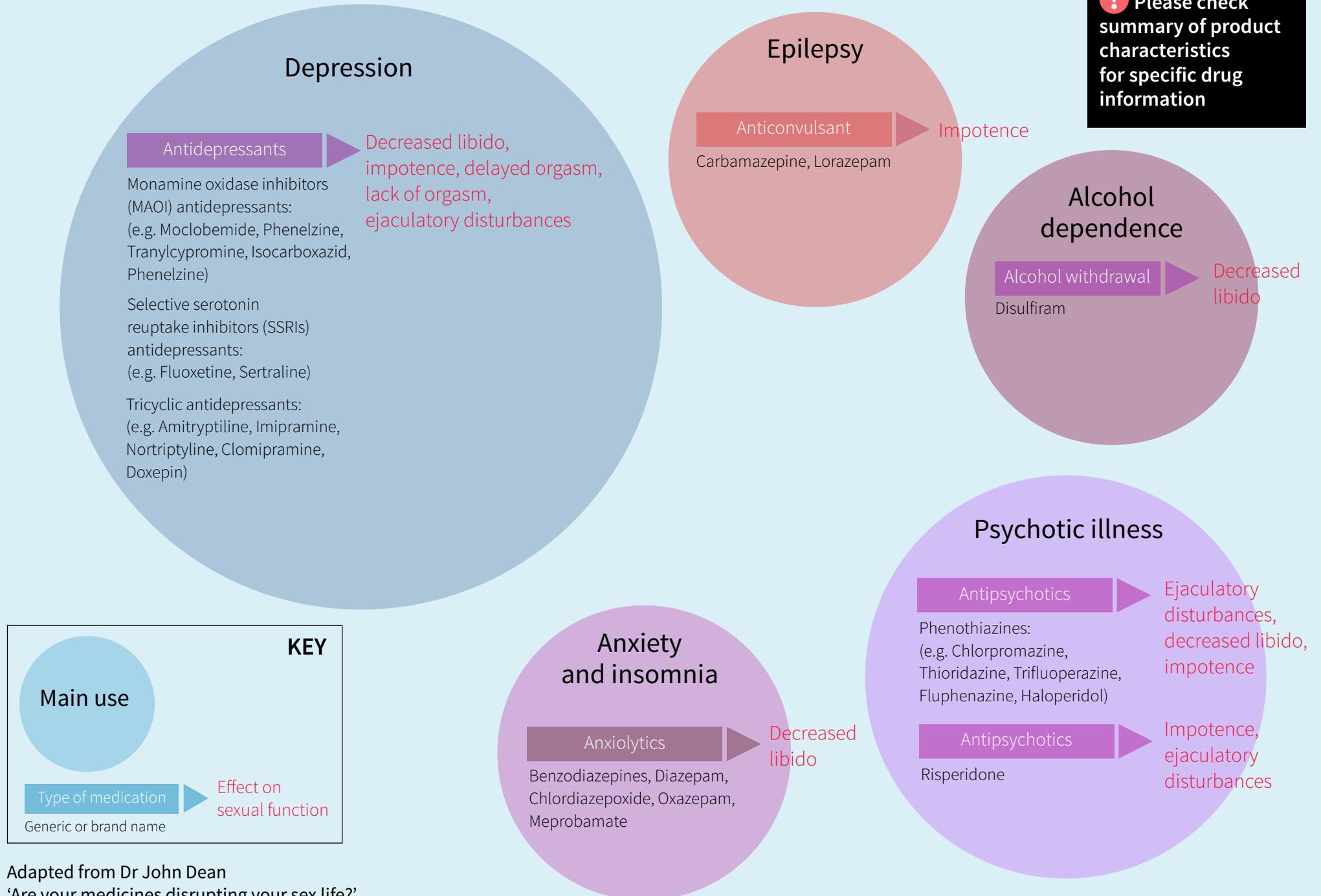


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## Anti-depressants/ Psychotics/ Convulsants

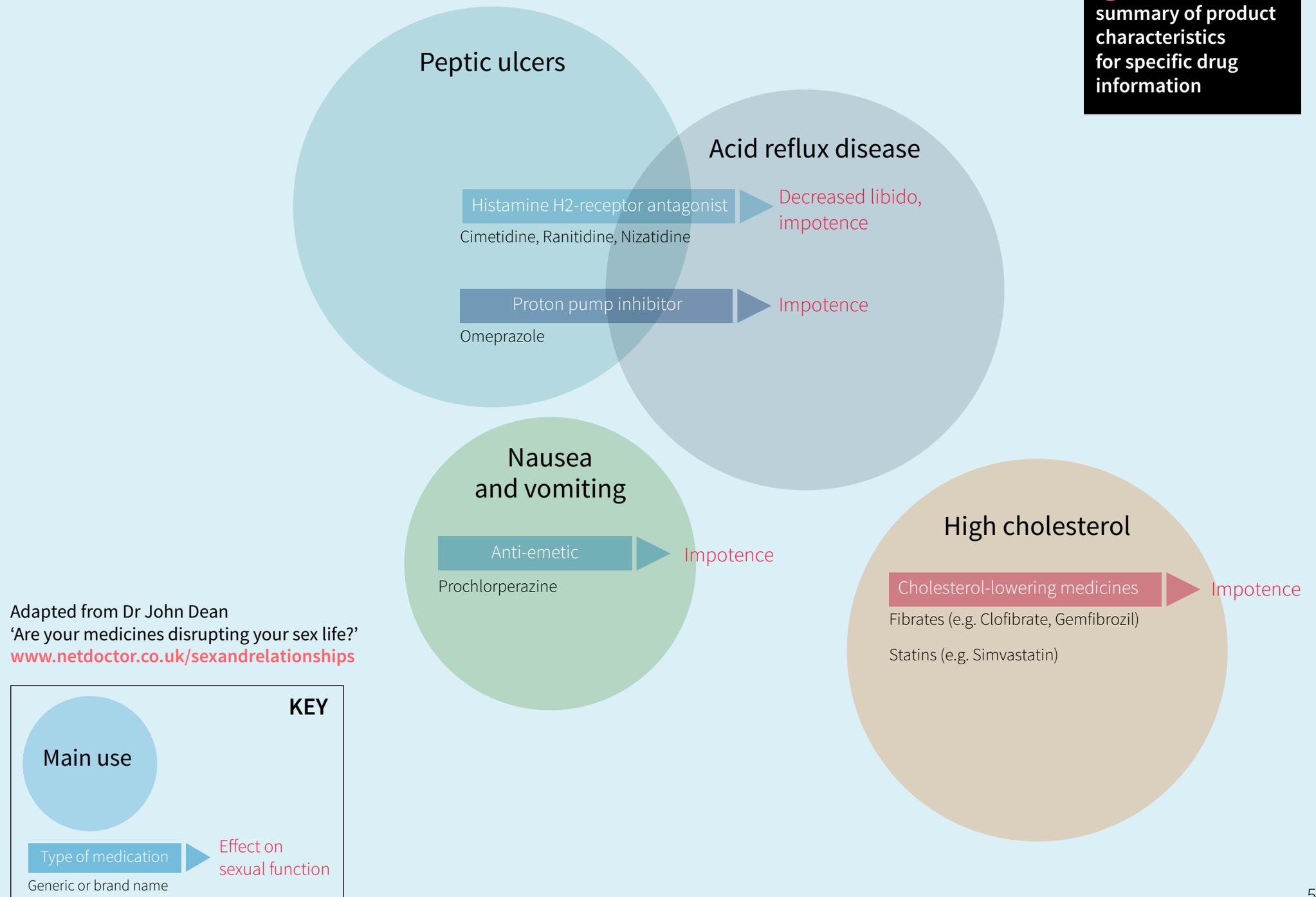


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## Gastro Intestinal

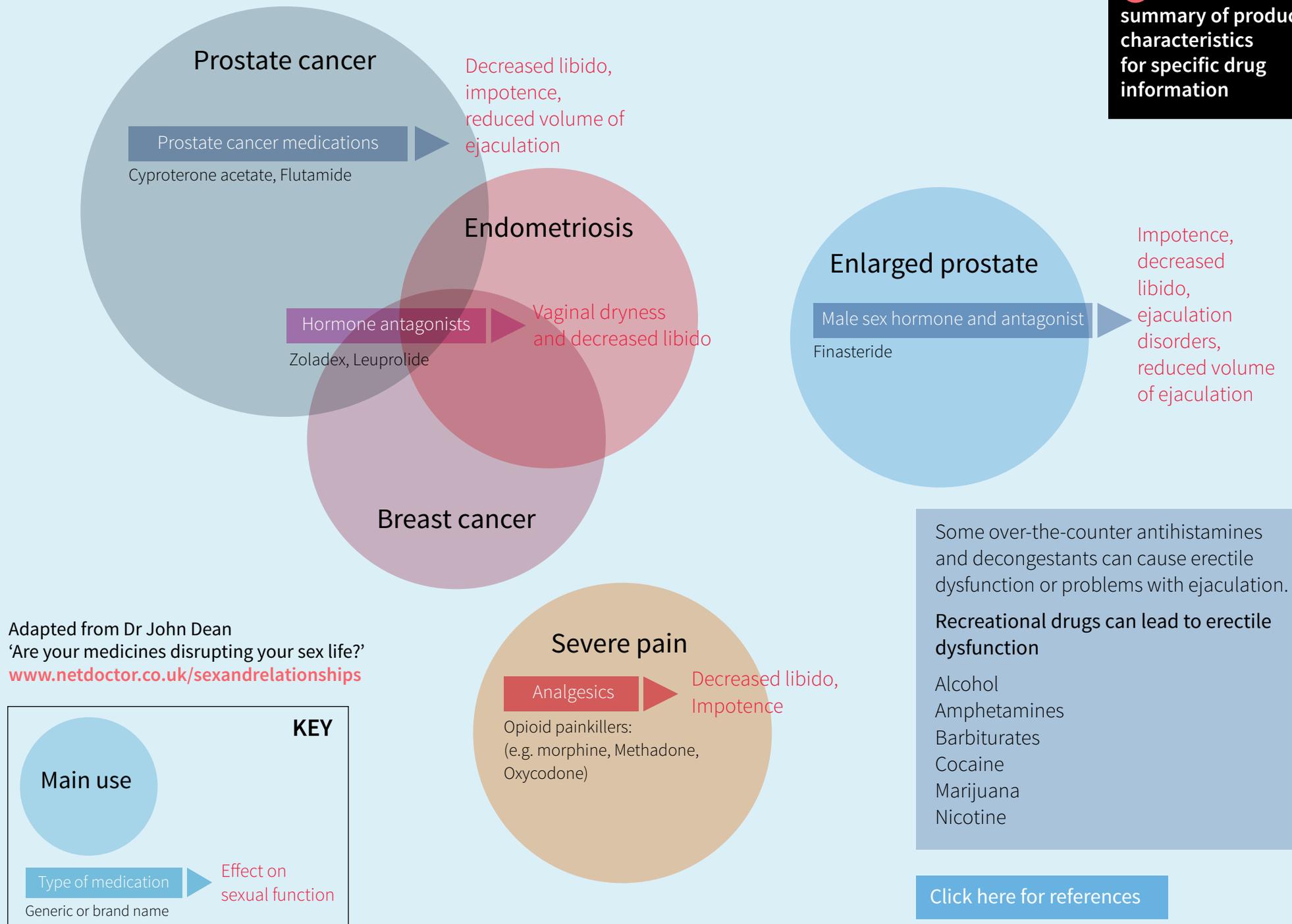


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## Oncology/ Pain



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## Case study: Mrs M

Mrs M, aged 56, has had MS for 20 years, and was reporting extensor spasms in her legs, affecting her quads as well as adductors. She was using Baclofen.

Having reviewed the patient and partner, one question I asked was whether intimate relationships had been affected as a result of her MS. She explained that they were 'past it' and it was not a problem. Her husband telephoned me after doing the review. He had not wanted to discuss it in front of his wife but explained that he wanted more intimacy, but did not want to hurt her in any way physically, and therefore did not discuss the subject with her in case he offended her.

I explained the different medications that can be used in spasticity and that people with spasm can still have sex if the right medications are used. I suggested that they discuss it and come back to me if the Baclofen was not helping.

I then got a phone call from Mr M, who said that he had approached his wife, who was delighted he wanted to be more intimate and that the spasms did not hurt but were unpredictable in their intensity.

I arranged for the consultant to see them about corrective injections, since two or more muscle bundles were affected.

She had the injections, which improved the muscles, and now they are working to rekindle their sex life at her pace.

**“Mr M said that he had approached his wife, who was delighted that he wanted to be more intimate.”**

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“Encourage patients to plan the sex more, so they are more likely to achieve pleasure and enjoyment. They do not have to tell their partner about the preparatory time.”

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## 9 Practical strategies to suggest to the patient

It is common for people with MS-related disabilities to worry that they cannot satisfy their partner because of the range of sexual difficulties they could be experiencing. Equally, partners of people with MS may feel that spasms, pain, catheters prevent them giving pleasure in the way they used to. Many are scared or apprehensive.

Many women in the general population report low sexual desire, particularly in established relationships. Gila Bronner (2010), a sex and relationship therapist, advises that women are often drawn to sexual intercourse because they want love, closeness and intimacy. Their desire is activated once they engage in sexual activity. Many say the pleasure from sex makes orgasm less essential, although feel, nevertheless, that if they do not achieve orgasm, one or both partners has failed, sexually.

Studies of human sexuality show that manual stimulation of the genitals is generally more effective in producing the appropriate physical sensations than intercourse, since manual stimulation allows greater control. (Appel, 2010). Men who experience erectile problems find that more foreplay produces a more sustainable erection.

Spontaneous sex is not so easy when someone has MS. Instead, encourage patients to plan sex more, so they are more likely to achieve pleasure and enjoyment. They do not have to tell their partner about the preparatory time.

“Many say the pleasure from sex makes orgasm less essential, although feel, nevertheless, that if they do not achieve orgasm, one or both partners has failed, sexually.”

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## Before having sex

### Timing

- Encourage patients to plan sex when they have most energy – in the morning or after an afternoon nap. Although it's common for sex to be initiated at night, this is not ideal if someone suffers from fatigue.
- Advise the couple to allow enough time so they don't feel rushed.
- Sex is tiring. Recommend it might not be a good idea just before going out.

### Medication

- Propose that patients plan when to take medications for spasms, pain or erectile dysfunction.
- Anti-spasmodics should be taken an hour before intercourse.
- Medication for erectile dysfunction should be taken 15-30 minutes before. It lasts from four–36 hours.
- Remind men that PDE5 drugs for erectile dysfunction (Viagra, Levitra, Cialis), increase the likelihood of an erection but sexual stimulation is still necessary.
- There is no evidence that this family of drugs is effective for increasing female desire or orgasm. Studies of Sildenafil in women report benefits are limited to an increase in lubrication. (Dasgupta et al, 2004)
- Sildenafil is not prescribed in the UK.



### Environment

- Environment is important for relaxation and to appeal to other senses such as smell and taste.
- Suggest relaxing music, burning essential oils, candlelight for atmosphere and tasty snacks so the couple can feed one another.
- Recommend removing as much hospital equipment as possible.
- Suggest experimenting with cushions, pillows and wedges for comfort.
- Slings and swings can help with positioning.

## 9 Practical strategies to suggest to the patient

### Continence

- Discuss the need to empty bowels beforehand. If Peristeen or enemas are used, the patient should time these so the bowels are empty. Catheter bags and stomas should also be emptied. Using catheter valves allows urine bags to be removed.
- Encourage the patient to have towels available to put underneath them or use afterwards.
- Specialist continence pads are useful. The 'Connie Mate Bedpad' can absorb two litres of fluid over eight hours and has a breathable PUL waterproof backing.
- Peg tubes and suprapubic catheters can be tucked out of the way in attractive underwear, such as crotchless pants that can be kept on all the time.
- Men who have indwelling catheters can use a valve to prevent it leaking, then bend the catheter over the penis.
- A condom over the penis and catheter is more comfortable for both and some partners report an increase in sensation.
- Women with a urethral catheter should use a valve and move it to the side.
- Encourage partners to feel fresh and smell nice – perfume or aftershave can stimulate arousal.

### LINKS

Continence pads [www.conni.com.au](http://www.conni.com.au)

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## Foreplay

This can be the most important part of the sexual act and all that is needed for sexual satisfaction.

For men in particular, foreplay is essential because the penis needs maximum stimulation before penetration.

Encourage patients to be open-minded as there are so many different things to experiment with. What may work for one person might put-off another. Encourage them to find out what works and be honest with one another.

## Porn

Used in the right situation and with mutual understanding pornographic books, magazines and DVDs can be helpful for lots of couples. Of course, porn is dramatised and a lot of it is probably not physically possible to re-enact.



“Encourage patients to be open-minded as there are so many different things to experiment with.”

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## Sex toys

There is an abundance of sex toys for men and women. Experimentation is fun.

### Men

- **Artificial Vagina** – These can be useful for masturbation, especially if a partner has impaired hand function.
- **Viberect** – Vibrator that stimulates the penis [www.youtube.com](http://www.youtube.com)
- **Sleeves** – Also used for masturbation. They come in different tightnesses and materials – e.g. ribbed, smooth, etc.
- **Prostate Vibrator** – Used rectally to stimulate the prostate gland.
- **Humpus** – Has attachments for male and female masturbation.
- **Vibrator** – To be used on the perineum.

### Both

Fantasy play works fantastically for a lot of couples, using storytelling, dressing up, etc. This is the time when they can be honest and share what they really like. Their fantasies might not be achievable, but the sharing can be fun.

### Women

- **Vibrators** – Come in various designs and sizes: from small bullet vibrators to simulate the clitoris, to penetrative vibrators to be used vaginally/anally with varying sizes and speeds.
- **Clitoral Stimulators** – These vary from small vibrating 'nubs', to ones that simulate oral sex. If the partner has reduced dexterity, there are stimulators that fit over a finger and just need to be held in place, as well as ones that can be kept in the palm of the hand.
- **Anal Plugs/Anal Beads** – Some women find the added sensation of anal penetration adds to sexual arousal.
- **Lubricants** – Experiment with different types of lubricants with varying smells and tastes. There are stimulating ones for people who may find achieving orgasm difficult and extra lubricating ones if dryness is a problem.

The history of vibrators is fascinating. Vibrators were designed by GPs more than two centuries ago to treat hysteria.

[www.psychologytoday.com](http://www.psychologytoday.com)  
[www.theguardian.com](http://www.theguardian.com)

For a detailed read about the 'job that no one wanted':

[www.nytimes.com/books](http://www.nytimes.com/books)

#### Read here for more about how lubricants were developed.

Lubricants need to be silicone-based. There are many on the market. KY jelly is not a lubricant of choice. Lubricants should not be oil-based as these are more likely to cause a UTI and they rot condoms. For information on natural lubricant go to [www.spokz.co.uk](http://www.spokz.co.uk)

- **Jiggle Balls/Ben Wa Balls** – These fit inside the vagina and are good for practising pelvic floor exercises.
- **Clitoral Pumps** – Used to increase blood supply to the clitoral area to heighten sensation.
- **Toothbrush attachment** – This may or may not work, but is cheap. Go to [www.spokz.co.uk](http://www.spokz.co.uk)
- **Gripping aid** – Can help if hand function is impaired. [www.spokz.co.uk](http://www.spokz.co.uk)



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## Sex Itself

Mutual masturbation can lead to a more intense orgasm than penetrative sex. Patients can experiment with lubricants, oils, props – e.g. feathers, etc – and oral sex if possible. Remind patients that if they don't manage penetrative sex, it doesn't mean their relationship is any less satisfactory.



## Positioning

It is important for patients to find a position or positions that take into account spasms, pain, weakness, etc. Encourage experimentation to identify what works best – this doesn't have to be flat in bed. Sex works just as well sitting in a chair or on the floor propped up with bean bags or cushions.

Cushions, various slings and swings are available online to help with positioning: [www.spokz.co.uk](http://www.spokz.co.uk)

### Women

A pillow underneath her bottom raises her hips and makes penetration easier for her partner. She can be uncomfortable lying flat on her back and it increases spasticity. Alternative positions, such as spooning with the partner, allow for penetration from behind. Spooning allows access to the clitoral area as well as breasts for extra stimulation. If the couple want anal sex this could be a good position.

### Men

It isn't always necessary for the man to be on top. He can sit in a chair or propped up on cushions or beanbags with the partner straddling his lap, either face to face or with her back to him. This last position allows the man access to his partner's clitoris and breasts for extra stimulation and is good for anal penetration.

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## Medication for men



### 1. Viagra (Sildenafil)

- Viagra is the most popular PDE5 inhibitor.
- Estimated to have worked for 20 million men worldwide.
- Administered in 25, 50 and 100mg doses.
- Taken one hour before sexual intercourse.
- Maximum dose is once daily.
- Effective from 30 minutes to four to five hours, but can work for up to 12 hours.
- Side effects include: headache, facial flushing, dyspepsia, dizziness, rhinitis and abnormal vision.
- Should be taken on an empty stomach.

### 2. Cialis (Tadalafil)

- Oral dose can be administered daily, either 10mg or 20mg doses.
- Tadalafil can be taken at least 30 minutes before sexual intercourse. It can now be prescribed as a daily dose.
- It works for at least 36 hours.
- Improved erections reported by 81% of treated men.
- Side effects include: headache, flushing, rhinitis and back pain/myalgia.
- Safety concern: it also serves as an inhibitor of PDE11, an enzyme in the testes, so there is concern about the effect that it has on sperm and spermatogenesis.
- May be taken with or without food.

### 3. Levitra (Vardenafil)

- Administered orally in five, 10 and 20mg doses.
- Maximum dose administration frequency is once daily.
- Effective from 30 minutes to four to five hours after administration – can work in just 15 minutes.
- 75% success rate.
- Treatment with vardenafil in patients with erectile dysfunction that were previously unresponsive to sildenafil produced significant improvements in erectile function domain score and maintenance of an erection.
- Side effects include: headache, flushing and rhinitis.
- May be taken with or without food.

## 9 Practical strategies to suggest to the patient

All three of these drugs are known as phosphodiesterase-5 (PDE5) inhibitors. By blocking the PDE-5 enzyme, these drugs help the smooth muscles of the penis to relax and increase blood flow. PDE5 inhibitors are not suitable for everyone. Men who take nitrate drugs for angina, or certain types of alpha-blockers for high blood pressure and benign prostatic hyperplasia, should not take PDE5 inhibitors. The PDE5 inhibitors are less effective in men with diabetes and in men who have been treated for prostate cancer.

Success rates increase with the number of attempts, so a man should not be discouraged if the drug does not work at first.

Men with the following conditions should not take PDE5 inhibitors without the recommendation of their doctors and even then should use them with caution: severe heart disease, such as unstable angina, a recent heart attack, or arrhythmias; recent history of stroke; hypotension; uncontrolled hypertension; uncontrolled diabetes; severe heart failure; retinitis pigmentosa. (With this genetic disease, people do not produce phosphodiesterase-5 and do not respond to PDE5 inhibitors.)

**! Please check summary of product characteristics for specific drug information**

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## Other pharmacological strategies for men

### 1. Transurethral Therapy (Alprostadil – MUSE)

- Mechanism of action: vasodilator.
- Administration: 125, 250, 500, 1000mg.
- Insert in the urethra.
- Erection occurs 5–10 minutes later.
- Erection lasts 30–60 minutes.
- Results: 10–65%.
- Side effects: Pain, bleeding, priapism (<3%).

### 2. Intracavernous Injection Therapy e.g. Caverject or Viridal

- Mechanism of action: smooth muscle vasodilator.
- Administration: 10, 20, 40mg.
- Inject directly into corporeal bodies of the penis.
- Results: 70–90%.
- Dropout rates: 25–60%.
- Side effects: pain (36%), priapism (4%), fibrosis.

### 3. Vacuum Therapy

- Erection limited to 30 minutes.
- Results: 80–90%.
- Contraindications: bleeding disorders, sickle cell disease, anticoagulation.
- Complications: coolness, petechiae, numbness, pain with ejaculation.
- High drop-out rate.

### 4. Penile prosthesis

- Two or three piece.
- Low morbidity.
- Low mortality surgery.
- Low complication rates.
- High success rates – 5% malfunction rate at five years.
- High satisfaction rate – 87%.
- High partner satisfaction rate.

**! Please check summary of product characteristics for specific drug information**

#### LINKS

Men's Health Magazine. Five secrets of sexually satisfied women. [www.menshealth.com](http://www.menshealth.com)

#### FURTHER READING ON BEING SINGLE WITH MS AND HAVING SEXUAL DYSFUNCTION

Appel JM (2010). Sex rights for the disabled? *Journal of medical ethics*, 36, 152–154.

## Sexual strategies for women

These focus on what works for an individual but some strategies are worth considering even if their only result is improving communication between the couple.

Women with MS-related sexual dysfunction report fluctuating, reduced or no genital sensation so the HCP should discuss how the patient is going to achieve pleasure from non-penetrative sex. Many women find this difficult to accept, so this discussion must be open and frank. Not all women will be able to have penetrative sex or orgasm. Some feel sex is incomplete because of this (Koch et al, 2002) so it is important patients are able to explore other ways of feeling sexually fulfilled and learn new ways to become aroused.

[Click here for references](#)

## Vaginal dryness

- The patient should have plenty of lubricants available to apply liberally and use several times during sex. Silicone-based lubricants are good and can be bought over the counter. They are slippier and come in different flavours, such as peppermint, which can enhance sensation. It is important to explain how these should be used.
- Replens suits post menopausal women. It is a long lasting vaginal moisturiser, rather than lubricant, which helps regenerate the cells of the vaginal wall and encourages lubrication. Used twice a week, it replenishes vaginal moisture for up to three days. It can be bought over the counter or prescribed.
- Oestrogen-based vagi fem pessaries can be prescribed for dryness. They only release the hormone in the vagina.

Oil-based lubricants are inadvisable – they cause bladder infections and damage condoms.

## Foreplay

Many women find foreplay the most exciting part of sex. Discuss how they can gain pleasure from intimate fondling, mutual massage and oral stimulation.

Incorporating massage and passive exercises into foreplay can help with muscle tightness and spasticity in lower limbs.

## Sensate focus

This detracts attention from the genitals and encourages couples to discover other areas of the body that can lead to a degree of

sexual enjoyment. These areas may not be as orgasmic but can produce pleasure and guide the couple away from areas that have become dysfunctional.

- Guided imagery, exploring sexual fantasies and role play increase arousal and libido.
- Different sexual positions can produce more pleasure or be more achievable particularly for people experiencing spasticity and adductor spasm. Women who acknowledge the need to experiment find sex improves.
- Using a vibrator on clitoral, perineal or anal areas can increase pleasure. Mains operated vibrators are likely to be more effective. Too high a hertz can cause spasms in women with increased muscular tone. HCPs should discuss which vibrator is appropriate – some patients find phallic styles more helpful, others may prefer non-penetrative designs. Women can be wary about using vibrators – normalise them. It is not dirty to use one.
- Women patients with fatigue are more likely to experience sexual dysfunction (Fraser et al, 2008). Ways of conserving energy and managing fatigue include taking a cool shower or having a rest before sex, having sex in the daytime rather than evening. Brief intercourse can still be enjoyable.
- Some women experience repeated urinary tract infections as a result of sexual intercourse. The HCP can offer general advice but if this does not help, refer the patient to a urologist who may recommend antibiotics.

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‘When it comes to sex, it’s not the destination that counts—it’s the journey’

MIMI MOSHER, MS PATIENT

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## 10 How to maintain or restore intimacy

### What is intimacy?

Intimacy is not just about having intercourse or orgasms – it is much more than this. Intimacy involves caressing, kissing, mutual masturbation and self-masturbation. It includes being able to talk openly in a relationship about feelings without fear. Intimacy does not always need words but being able to put feelings and emotions into words makes intimacy more likely.

### Why is intimacy important?

Intimacy is important for sexual intercourse. It helps maintain communication and this can make sex more enjoyable. It is important to say “I love you”, as the way a person behaves may not always be enough.

### Effects of MS on intimacy

Someone with pain/fatigue/spasticity/dysfunction is likely to avoid intimacy as they fear sexual activity. This can have profound consequences for relationships.

### How does it affect relationships?

A lack of intimacy in a relationship leads to breakdown in communication. This can generate resentment and the relationship fails. It is less likely that sex will take place.

### How can intimacy be restored?

Talking. Individuals’ bodies change, become painful or numb. Unless this is shared, how will a partner know? Encourage the patient to speak to their partner about difficulties and fears. Suggest speaking to friends. Perhaps the problem happens to other couples that don’t have MS in the relationship.

If a couple finds it difficult to talk, they could start by writing down thoughts. This may make it easier to share. Writing helps if a patient has difficulty with word-finding, or memory problems. It is important to do this at a time of day when a patient is relaxed and least likely to be interrupted – e.g. before children get home from school.

HCPs may be able to offer practical solutions. A referral to a sex therapist may help, or RELATE.

Encourage patients to speak to others with MS or partners of those with MS. They may find the problem is not unusual and they may receive some practical advice.

“Intimacy includes being able to talk openly in a relationship about feelings without fear.”

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## Romance

Suggest making a date or playing a game. Ensure there is time as a couple, especially if there are children in the relationship. Ensure the patient makes at least one night a month 'date night'. Even if it is not possible to go out they can watch a movie at home and have a romantic dinner or takeaway. When the couple gives each other time, this helps create an environment where it is safe to talk. Candles or music can help the atmosphere, flowers too.



## Massage and physical contact

When there are difficulties in a relationship, couples stop touching. If this has been absent the couple could start by holding hands or having a cuddle. Touch is an important way of restoring intimacy. It can progress to massaging each other, which is relaxing and in turn helps relieve other symptoms such as pain and spasticity. If possible, sharing a bath can restore physical closeness.

## Changing roles

If a partner is also a carer, it can be difficult for both to switch between roles but it is important. Using signals can help - wearing an apron for certain jobs. Social services may support some tasks, especially personal care. This can help differentiate the roles and provide the energy to be intimate.



## Feeling sexy

It is common for people with MS to stop feeling sexy, especially if there are changes in body image or their role in the family. A woman may stop wearing make-up, as it's too difficult to apply or it takes too much energy. But she might have eyelashes tinted rather than trying to apply mascara, or have a wax if it's too difficult to shave. She might try a new haircut. Exercise or relaxation can also help someone feel sexy again.

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## Body mapping

Sensory body mapping explores the exact location of pleasant, decreased, or altered sensations caused by MS symptoms. Body mapping is used to help compensate for primary (genital) or secondary (non-genital) sensory changes, but it can be a useful first step in enhancing physical pleasure, emotional closeness, sexual communication and intimacy.

### To conduct a 'sensory body mapping' exercise (15 – 20 minutes):

The patient begins by systematically touching the body from head to toe (or all those places the patient can comfortably reach). Suggest conducting this exercise without clothes on, in a place that is private, relaxing, and a comfortable temperature. The patient should vary the rate, rhythm and pressure of touch, note areas of sensual pleasure, discomfort, or sensory change and alter pattern of touch to maximise the pleasure that can be felt without trying to obtain sexual satisfaction or orgasm.

Next, the patient informs their partner of their 'body map' information and instructs him/her in touching them in a similar fashion. The partner can provide the same information about his or her 'body map'. They should take turns providing pleasure without engaging in sex or trying to orgasm. The emphasis is on communication and pleasure, not sex or orgasm.

Massaging with essential oils and being very sensual might be all a person desires to make them feel sexually satisfied.

These sexual exercises can help restore relationships. They can be non-sexual or sexual. They ban intercourse and masturbation but help to improve lines of communication. There are three stages: non-genital sensate focus, genital sensate focus and penetrative sensate focus. The exercises help re-build intimacy before progressing to sexual intercourse. They start by encouraging couples to touch each other, initially avoiding the genital area, but later progressing to the genitals. Finally penetration is allowed, which does not just include penile penetration but the use of fingers or sex aids.

#### LINKS

More about body mapping [www.healthcentral.com](http://www.healthcentral.com)  
[www.counselling-matters.org.uk](http://www.counselling-matters.org.uk)

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### Tantric sex

This involves arousing all five senses of sight, taste, touch, scent and hearing. It is about the moment and not the end goal. It helps to set the scene for intercourse to happen and helps the couple get to know each other again.

### Masturbation

This gives someone a chance to explore their body and find out what gives them pleasure. It makes it easier to communicate what he or she likes and builds confidence. If the patient doesn't know what gives him or her pleasure, it is difficult to teach someone else. It is important to not feel ashamed or embarrassed, to relax and enjoy the sensations.

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“Being diagnosed with MS quickly alters a person’s norms – walking, driving, working, and of course expressing themselves sexually, either as an individual or within a relationship.”

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## 11 Sexual diversity: what is normal?

Healthcare workers assume their beliefs are normal, but unless they are prepared to accept other versions of that norm, they are unlikely to develop a therapeutic conversation with the patient.

Being diagnosed with MS quickly alters a person's norms – walking, driving, working, and of course expressing themselves sexually, either as an individual or within a relationship.

So norms change with time and circumstance. And although everybody has their own version of normal, differing across cultures, religions and even individuals, most adults feel that their norms are standard for the society they inhabit.

In sex and intimacy, normal can be defined as a negotiated agreement between consenting adults that all parties feel comfortable with.

Communication is central to the development of this agreement. It is therefore essential that, as a person's abilities and needs change with MS, the partner is aware of these changes.

The MS specialist nurse/practitioner can facilitate this discussion. Care and nursing home staff might also contribute, as they may be needed to enable the relationship. Quite often this is an uncomfortable topic for all parties. It takes trust, tact and relies heavily on the relationship between the patient, the partner and the HCP.

An in-depth knowledge of the couple's background, as well as cultural and religious influences, is useful. The EX-P-LI-SS-IT model forms an excellent assessment tool to explore these complex issues.

“In sex and intimacy normal can be defined as a negotiated agreement between consenting adults that all parties feel comfortable with.”

## Pornography

For many, pornography has negative connotations such as exploitation, abuse or something that is sleazy or dirty. For others, it is acceptable, even exciting, within certain limits. To different people, the point at which pornography or nudity becomes offensive differs wildly.

Societal norms have shifted, although many people are offended and concerned about the depiction and possible exploitation of participants in porn websites.

Appearing shocked or judgemental when a patient expresses their desires or use of pornography may harm communication. Therefore, the MS nurse/practitioner should consider how they may react to these conversations, in order to prepare adequately.

A sound knowledge of the ethnic and cultural make-up of the caseload is extremely useful.

Erotic fiction is not new, but was propelled into the mainstream in 2012 when the novel *Fifty Shades of Grey* sold 100 million copies worldwide. It enabled women to be more comfortable discussing sexuality and desire. Its presence in supermarkets, major book chains, on public transport and as a topic of conversation in workplaces created a minor social revolution, spreading the idea that it was possible to be more sexually creative. Sex therapists have acknowledged that erotic literature and sexual fantasy can help women focus on sex and reach orgasm.

But fiction is not the only source of fantasy and role-play. The Internet offers simulated worlds that individuals and couples can involve themselves in and redesign their images. An avatar can prove to be a stimulating and attractive reality.

### Sexual awareness

However the use of the Internet to access pornography raises questions about its influence on some people's perceptions of sex.

A sexually inexperienced or young person may be at risk of forming an extreme or risky view of what is normal if his or her only access to sexual information is via pornography sites.

A report by the Office of the Children's Commissioner (2011) provides evidence that exposure to pornography does influence children's attitudes to relationships and sex. Commissioner Maggie Atkinson has pointed out that violent and sadistic imagery is readily available to very young children, even if they do not go searching for it. The fact that porn is everywhere reveals a high correlation between exposure to pornography and its influence on children's behaviour and attitudes.

The HCP should therefore be aware of this trend and be prepared to discuss the role of fantasy in sex and the potential dangers of more extreme fantasy.

Smartphones, tablets and PCs have made internet porn increasingly the easiest source, but this also offers access to material that a

## 11 Sexual diversity: what is normal?

decade ago would only have been accessible via extreme fetish clubs.

Some people are using the Internet to film their live sexual encounters and inviting others to do the same. There is an Internet site linked to Facebook for those who want to take 'selfies' before, during or after sex. Times and attitudes have changed. For example, it is acceptable for women to openly read stories of sexual domination and sadomasochism in public.

### Information

Being a safe, non-judgemental source of information about sex, which takes into consideration knowledge of the person's neurological sexual dysfunction, is a very valuable part of the MS nurse/practitioner's role.

“Smartphones, tablets and PCs have made internet porn increasingly the easiest source.”

#### LINK

Protecting children [www.thesundaytimes.co.uk](http://www.thesundaytimes.co.uk)

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“Fantasy and role-play may be an integral part of a couple’s relationship, particularly if one of them is less physically able.”

## Fantasy

Fantasy and role-play may be an integral part of a couple’s relationship, particularly if one of them is less physically able. The internet also offers simulated worlds where a person can redesign their image. This use of an avatar can prove to be a more stimulating and attractive ‘reality’.

There is often a focus on how the male develops opinions and attitudes to sex. As most people with MS are women, perhaps HCPs should focus more on the female libido and attitudes.

Tracey Cox is a relationship therapist and her book *Dare* highlighted the difficulty and problems of turning an erotic daydream into reality. Her book looks at 20 couples who each discussed their fantasy and reveals how some were able to play them out successfully. She concluded that fantasies are a very powerful way of spicing up a relationship.

## 11 Sexual diversity: what is normal?

### Arousal

Other research studies have shown that women are more likely to under-rate their reported arousal and to base their answers on what arouses them on value judgements and expected norms (Chivers et al, 2004). When the same studies were run with males, they were much more likely to rate their arousal in line with the actual physiological responses. The level of privacy was very significant to the females, whereas it was mostly irrelevant to the males.

So, although attitudes have moved on, it would appear, nonetheless, that women still feel more constrained revealing their desires or needs. When working with females, it may be useful to bear this in mind. However, trusting and feeling safe is a fundamental need in both sexes.

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## Safety and risk

### What is safe?

Sex is fun, natural, and a great form of exercise. As with many fun things, however, it is not without risk.

#### Choose sexual partners with care.

It has often been said that having sex with someone is like having sex with everyone they've ever been with.

#### Appropriate protection reduces the risk of infection.

Make sure the patient knows how to use a male condom properly for the lowest possible risk. Female condoms are used for penetrative vaginal sex. Dental dams are used for oral sex on female genitalia or the anus. Make sure condoms and dental dams do not have any holes, tears, or other damage.

#### Appropriate contraception reduces the risk of pregnancy.

Unless two partners are both completely monogamous and free of STIs and HIV, contraceptives should be used in conjunction with condoms to prevent the transmission of infection. The incidence of sexually transmitted diseases is increasing in the over-fifty age group (RCN, 2011).

#### Take care when experimenting with anal sex.

Anal sex is a riskier type of sex than vaginal, although many couples (gay and straight) derive pleasure from it.

#### Keep toys clean.

Sex toys must be kept clean and hygienic. Advise patients to rinse the toys well and be sure to dry them before storing them in a sealed bag.

#### Get tested regularly.

Suggest patients go to their doctor or a free clinic regularly to make sure they haven't contracted HIV or any other STIs.

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## Case study: Miriam

I can't walk, I can't stand up, my right arm doesn't work at all, my left arm is weak and only partially works. I have a lot of spasticity. I have different energy levels throughout the day; I have more energy first thing in the morning and last thing at night. This limits how much I can do in the day. I'm very affected by the heat; my muscles get weaker, my speech becomes slurred, I can't think clearly, I get very easily overwhelmed, my mind feels foggy. My skin is very sensitive at the moment and I'm having real problems with blisters. I have a suprapubic catheter and I have occasional urine and bowel incontinence.

I started with relapsing-remitting MS with very few symptoms, then after about 12 years I moved to secondary progressive MS. I have now been a full-time wheelchair user for 14 years. I am a 50-year-old female who has been married for nearly 20 years.

Sexually, MS affects me because it takes me longer to have an orgasm. I can still have one but it is not as strong or of the same sort of quality. I am quite limited in what I can do, as my arms and hands don't work properly. So this means I cannot masturbate my partner (or myself), caress him fully, hug him, pull him towards me – many things that I feel really sad about and wish I could. I cannot move my body freely in bed, which limits how I can move or position myself for sex. I can't be proactive in the sexual partnership. I can't physically initiate non-verbal sexual communication or movement, or touch. This loss of what I can do for my husband and what it is like for him is what I find deeply distressing, as well as what I can no longer do for myself.

Talking with my husband, talking to other disabled people, reading about disability and sex, running workshops and giving presentations on disability and sex and intimacy – doing all these things, I have learnt a lot about myself, and about the issues facing people where disability is part of the equation in a sexual relationship. I have learned about experimenting with different sex toys and the importance of counselling (with organisations like Outsiders and Sexual Health and Disability Alliance). I have also met people who are involved in sexual work, as sex therapists, sex workers or with Tantric massage.

“I have learnt a lot about myself, and about the issues facing people where disability is part of the equation in a sexual relationship.”

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“People with disabilities may feel paying for sex is the only option. A thoughtful discussion about the pros and cons of this – including ethical, legal, and sexual health issues – will be beneficial.”

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# 12 Law and ethics

## Mental capacity

### What is my duty of care and how does the Mental Capacity Act work?

MS specialist nurses have a duty of care under the NMC Code of Practice to always act in our patients' best interests, but what if we feel that the situation is further complicated by cognitive problems?

The Mental Capacity Act's philosophy is to ensure that any decision made or action taken on behalf of someone who lacks capacity, is made in their best interests. It aims to balance an individual's right to make decisions for themselves with their rights to be protected from harm. It comprises of five statutory principles which are listed below:

**Principle 1:** A person must be assumed to have capacity unless it is established that he lacks capacity (section 1.2)

**Principle 2:** A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (section 1.3)

**Principle 3:** A person is not to be treated as unable to make a decision merely because he makes an unwise decision (section 1.4)

**Principle 4:** An act done or decisions made under this Act for, or on behalf of, a person who lacks capacity, must be done or made in his best interests (section 1.5)

**Principle 5:** Before the act is done or the decision is made, regards must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.(Section 1.6) (Section 2.0, p20)

Even if it is established that the person in our care lacks capacity, sections 27–29 and 62 of the Act set out specific decisions that can never be carried out under the Act, whether by family, carers, professionals, attorneys, or the Court of Protection (Section 1.10, p16).

### Choice of partner

Nothing in the Act permits consent to marriage, civil partnership or sexual relations on someone else's behalf.

Nurses and practitioners are expected as professionals to have a good working knowledge of the Act. We are not legally bound to apply all of it but we cannot be ignorant of it. We would be expected to adhere to the five principles at the very least.

So, how can the Act help the HCP who feels that their patient is vulnerable and not making good long-term choices about who she has sexual relations with?

### A duty of care

The Act protects a person's rights to make their own decisions. It specifically states that choice of sexual partner will always be outside the remit of the Act. Principle 3 also enshrines the right to make a decision that others disagree with, be they family or professional.

The Act does, however, charge us with the responsibility to give all and any information, in whatever form is effective, to ensure the person can make an informed choice. In the above case, that information could be advice and guidance on contraception and sexual health. Perhaps more importantly, the Act states that the vulnerable person has a right to be protected from abuse and exploitation (section 1.11, p17).

If the HCP has concerns, ongoing monitoring with a view to safeguarding may be appropriate and is suggested under Section 4.53 (p60, Code of Practice MCA).

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## Cognition difficulties

Alterations in cognition such as forgetfulness, apathy and disinterest can have a significant impact on a couple's dynamics. Patients' concentration span can be reduced and they may lack insight into how their condition affects their partner. There are sometimes cases of hypersexuality (Gondim and Thomas, 2001).

HCPs often feel a patient affected cognitively may be taken advantage of. The RCN has a list of considerations for the HCP:

- Someone with cognitive problems may have sexual needs
- How does the Mental Capacity Act 2005 apply?
- Consent and autonomy
- Does the patient recognise their partner?
- Is the patient able to refuse sex? Can he or she express opinions?
- Ensure the patient's partner is aware of cognition changes and how this affects their ability to have an intimate relationship
- Support the patient's partner in how to read non-verbal communication, respecting fear or reluctance
- HCPs involved with the patient should meet and acknowledge the NMC 'Advocacy and autonomy' advice sheet
- Be aware of the need for confidentiality
- Monitor the patient's mental health,

particularly if they are anxious or distressed. (RCN booklet, 2011)

## Confidentiality

The Caldicott Principles cover all NHS employees. HCPs are also bound by their health professional council. In the UK, health confidentiality is a common law duty. HCPs should identify situations when confidentiality cannot be maintained such as to protect a child or if someone is at risk of abuse.

## Code of Standard

The NMC Code of Standards (2008) states that nurses:

- Make the care of people your first concern, treating them as individuals and respecting their dignity.
- Work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community.
- Provide a high standard of practice and care at all times, be open and honest, act with integrity and uphold the reputation of your profession.

*“Nurses and nursing staff treat everyone in their care with dignity and humanity – they understand their individual needs, show compassion and sensitivity, and provide care in a way that respects all people equally.”*

## RCN

The RCN (2014) has developed Principles of Care, the first of which states:

*“Nurses and nursing staff treat everyone in their care with dignity and humanity – they understand their individual needs, show compassion and sensitivity, and provide care in a way that respects all people equally”.*

## Disability and prostitution

### The risk of prosecution for an HCP

If a patient discloses their desire to pay for sex to meet their sexual needs, we as health professionals need to be prepared to discuss this openly and without judgement.

But HCPs risk prosecution under the Sexual Offences Act (2003) if we help a patient make arrangements to pay for sex. We would be in breach of the NMC code of Clear Sexual Boundaries (2008) and in the case of a care home, the provider or manager could be prosecuted for 'keeping a disorderly house'.

To be a sex worker is not illegal, but to solicit or financially profit from providing sex for people is.

People with disabilities may feel paying for sex is the only option. A thoughtful discussion about the pros and cons of this – including ethical, legal, and sexual health issues – will be beneficial.

### Funding sex with direct payments

Some individuals are using direct payments in order to fund access to the services of sex workers. The issue of access to sexual partners is very complex. The World Health Organization (2009) states that those with disabilities are 'as entitled to self-determination, confidentiality and respect as any other individuals' and that no one should be subjected 'to arbitrary or unlawful interference in their privacy'. Consequently, how an individual decides to spend their benefit should not be anyone else's business.

**“Under no circumstances should staff play any part in making arrangements for a sex worker as, in doing so, they may well risk liability for an offence under the Sexual Offences Act (2003).”**

The purpose of direct payments, according to NHS Choices (2014), is: 'to give you more flexibility in how your services are provided. By giving you money instead of social care services, you have greater choice and control over your life and are able to make your own decisions about how your care is delivered'.

### Human rights and sexual self-determination

The Convention on the Rights of Persons with Disabilities (UN, 2008) believes that those with disabilities who are capable of informed consent must enjoy all human rights and freedoms and adaptations have to be made to enable those with disabilities to exercise their rights. The Convention stipulates that the disabled have the right to sexual self-determination. The UN (2008) and WHO (2009) state those with disabilities need information regarding sexual and reproductive health and have the right to make decisions for themselves about any sexual activity.

### RCN guidance on access to health workers

The RCN (2011) is clear about the position of healthcare workers assisting patients to access the services of sex workers: 'Under no circumstances should staff play any part in making arrangements for a sex worker as, in doing so, they may well risk liability for an offence under the Sexual Offences Act (2003)' (RCN, 2011, p24).

### Patients can access sex workers independently

If competent individuals wish to access the services of sex workers independently, the TLC Trust (2014) provides information and access to sex workers.

#### LINKS

Disability and the oldest profession  
[www.ablemagazine.co.uk](http://www.ablemagazine.co.uk)

Family Planning Association [www.fpa.org.uk](http://www.fpa.org.uk)

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

Prostitution [www.politics.co.uk](http://www.politics.co.uk)

Disabled people and paid for sex – the issues  
[www.tlc-trust.org.uk](http://www.tlc-trust.org.uk)

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## Nursing homes

There is a great deal of discussion about individuals living in nursing homes being enabled to express their sexuality and participate in sexual activity. Heath (2011) suggests that they should have the right to consider their rooms as their home. Consequently, if they are consenting adults, they are entitled to participate in consensual relationships with other adults.

### Legitimate nursing activity

The RCN (2000, 2011) specifically states that 'addressing residents' sexuality and sexual health are appropriate and legitimate areas of nursing activity'.

The RCN (2011) has developed guidelines on sex and sexuality of older people in care homes, which could be used when caring for physically disabled individuals. The guidelines stipulate that care home providers should 'strive to offer environments which facilitate individual rights and choices in sexuality, expression and intimate relationships' (RCN, 2011, p2).

### The right to consensual relationships

Facilities that do not acknowledge the individual's sexuality or the need for intimate relationships can cause significant unhappiness. Individuals with physical disabilities will experience sexual feelings, fantasies, thoughts and desires just the same as able-bodied individuals (TLC Trust, 2014).

In nursing homes, individuals may have limited opportunity for sexual relationships. However, RCN guidelines (2011) suggest that individuals have a right to participate in consensual relationships in their own rooms, providing the relationship has no negative impact on other residents.

Heath (2011) believes nursing homes should develop policies promoting privacy and confidentiality. If nursing home patients or residents above the age of consent form attachments, providing both parties are competent, it is unethical for staff to discuss the relationship with any third party (partners, parents or children) because it breaches confidentiality.

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### Managing rights

The RCN (2011) outlines how rights can be managed within the care system:

- Residents should be permitted to remain in their rooms undisturbed.
- They should be free to lock their doors unless a medical condition dictates otherwise.
- Staff should always knock and wait for permission before entering a resident's room.

Heath (2011) suggests double beds and/or private accommodation should be available for conjugal visits.

However, sexual activity may prove difficult because of an individual's need for personal care – e.g. transferring, positioning, managing catheters, providing personal hygiene before and after sexual activity (Chance, 2002). It requires the involvement of the multi-disciplinary team (MDT) and a degree of negotiation between management, staff and the resident.

### Protecting codes of conduct with care plan

A care plan reduces the risk of individual HCPs breaching professional codes of conduct (RCN, 2000). For example, if nursing staff teach patients about masturbation, there must be a clearly documented rationale to demonstrate that there is no intent to perform an act of indecency or abuse of position by the nurse involved (RCN, 2009). Couldrick (2000) developed the

Recognition Model, which promotes the concept of the individual's sexuality being supported by the MDT, physiotherapists exploring spasticity and positioning, occupational therapists reviewing fatigue management and provision of equipment – e.g. vibrators – the speech therapist supporting communication between individuals.

Unfortunately, not all individuals living with MS maintain the ability to consent to participate in a sexual relationship. It is therefore imperative that they are protected from any form of abuse from relatives, staff or visitors. If at any time there is a concern regarding an individual's capacity, it would be necessary for a formal assessment to be completed and any necessary safeguards implemented.

#### FURTHER READING AND LINKS

Guidance for people in care homes.

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

## Sexual abuse

A HCP who is assessing a patient should consider sexual abuse, especially if someone is vulnerable or has cognitive difficulties. There is little written on sexual abuse in MS but there are resources available on sexual abuse of disabled people, particularly those with learning difficulties.

### Definition of sexual abuse

If a person is pressured to do something sexual against their will. It can range from unwanted touching or photographing to rape. There can be a subtle line between two adults experimenting and one person feeling pressured into a sexual act which he or she feels is degrading or frightening.

### Signs of sexual abuse

- Changes in behaviour such as fear and panic attacks. Depression, low self-esteem
- Refusing to see a particular person
- Developing an eating disorder
- Drug or alcohol use
- Nightmares
- Dreading medical examination
- Pregnancy
- Attempted suicide

### What is rape?

The sexual intercourse must be non-consensual. The definition applies to married couples as well as anal intercourse.

- Penile penetration does not have to include ejaculation.
- Lack of consent is sufficient—there does not need to be force, fear or fraud
- Consent means that a man or woman understands the nature of the act (there is some debate on what this means). It is an important consideration for patients with cognitive problems. If in doubt, ask the patient about the significance of sexual intercourse for them.

The Sexual Offences Act (2003) updated the law regarding consent: 'A person consents if she or he agrees by choice, and has the freedom and capacity to make that choice. The law does not require the victim to have physically resisted in order to prove a lack of consent.'

### Sexual assault

Sexual assault is defined in the 2003 Act as 'an act of physical, psychological and emotional violation, in the form of a sexual act, which is inflicted on someone without consent. It can involve forcing or manipulating someone to witness or participate in any sexual acts.'

### Taking action

Suspicions of sexual abuse in a vulnerable adult should be discussed with social services. You must report your concerns.

A local social services website will have guidance on how to do this. You will need to give details of:

- why you're concerned
- the patient's name, age, address
- who they live with
- if they are being helped by any other organisation
- who you suspect may be abusing the patient.

#### LINKS

For information and support about sexual abuse  
[www.mycareinbirmingham.org.uk](http://www.mycareinbirmingham.org.uk)

[Click here for references](#)

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“It doesn’t matter how old you are, if you are considering having sex you’ll need to consider contraception, and that goes for men too.”

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# 13 MS and Contraception

Multiple sclerosis is more common in women than in men. Questions about fertility, family planning and breast-feeding do arise as many women given an MS diagnosis are of child-bearing age.

Women on treatment for MS should use effective birth control. There is some evidence to suggest certain disease-modifying MS treatments are associated with a higher risk of miscarriage, and the effects on a developing baby or on fertility are unknown (see SPC for specific drug information). Aubagio is known to be harmful to the developing baby (see special warning opposite). Fingolimod also has potential for serious risk to the foetus. Women on Disease Modifying Therapy should be advised to use contraception.

Many women on therapy go on to start families at some point, so they should talk to a HCP about the options available.



## Patients who should not be supplied oral contraception

### Any contraceptive Pill:

- Women with undiagnosed irregular vaginal bleeding
- Women with suspected or proven pregnancy
- Women with hormone-dependant cancer
- Women with liver disease – e.g. porphyria chronic active hepatitis
- Women with recent molar pregnancy
- Women who are known to be unreliable, forgetful pill-takers

### Combined oral contraceptive (COC) Pill:

- Women with past or present circulatory disease – e.g. DVT, hypertension, MI, CVA, severe or combined risk factors for arterial disease (heavy smoking, age, obesity, uncontrolled diabetes)
- Women with crescendo or focal migraine, severe migraine requiring ergotamine – containing medication
- Women with chronic systematic disease – e.g. SLE, Crohn's
- Women who have had major surgery requiring immobilisation, orthopaedic/vascular procedures (both before and after)

### Progesterone-only Contraceptive (POP) Pill:

- Women with a history of ectopic pregnancy
- Women who need complete pregnancy protection

**! Please check summary of product characteristics for specific drug information**

## AUBAGIO – Teriflunomide

Aubagio, is known to be teratogenic. Patients should not take Aubagio if they are pregnant, think they maybe pregnant or are breastfeeding.

### Drug interactions

Aubagio may increase exposure of ethinylestradiol and levonorgestrel. Therefore, if taking Aubagio, patients should consider avoiding:

### Combined oral contraceptive Pills

- Mircilon
- Microgynon 30
- Cilest
- Ovysmen

### Contraceptive patch

- Evra

### Contraceptive vaginal ring

- Nuvaring

### Interuterine contraception

- Mirena IUS

### Emergency hormonal contraception

- Levonelle

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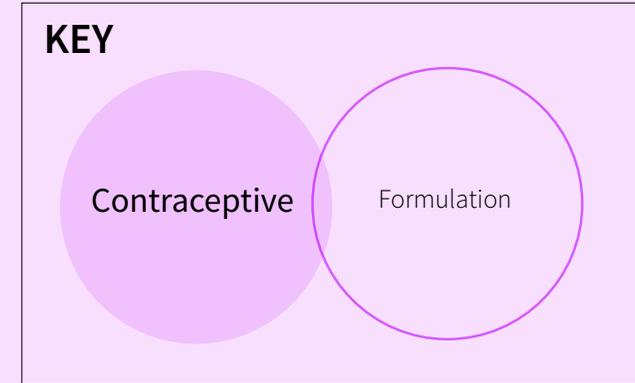
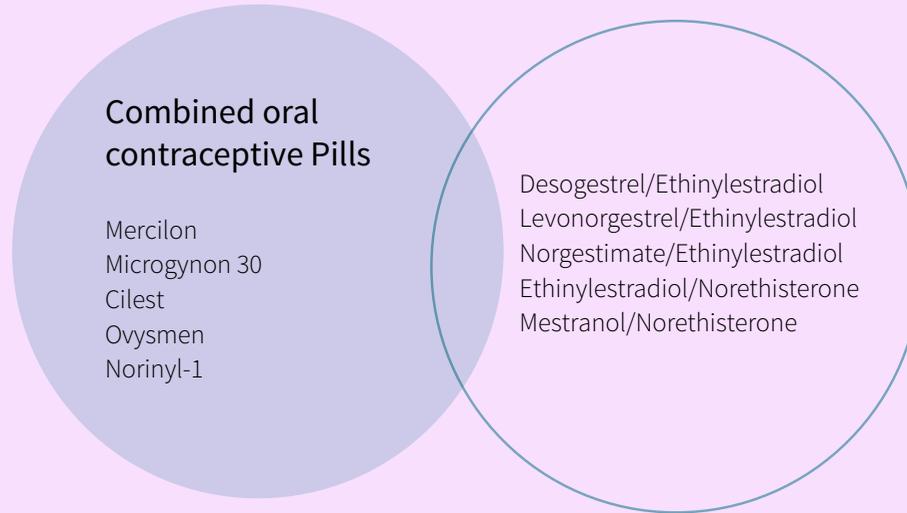
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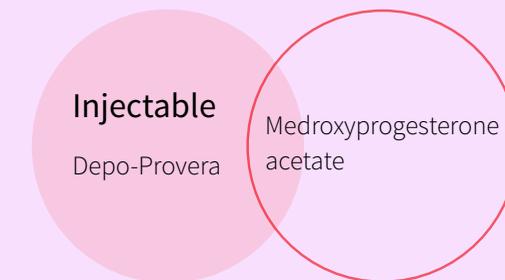
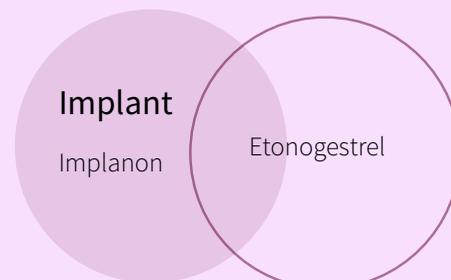
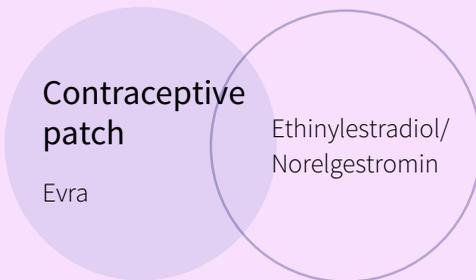
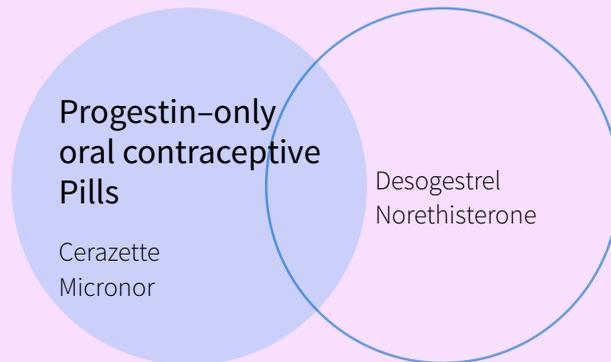
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## Long-acting reversible contraception (LARC)

LARCs are contraceptive methods that require administration less than once per cycle or month:

- Copper intrauterine devices
- Progesterone-only intrauterine systems
- Progesterone-only injectable contraceptives
- Progesterone-only subdermal implants

Effectiveness of barrier methods and oral contraceptive Pills depends on correct and consistent use.

LARC methods are more cost-effective than combined oral contraceptive Pills even at one year of use.

IUD, IUS and implants are more cost-effective than the injectable contraceptives.

### All LARC methods are suitable for:

- Nulliparous women
- Women who are breastfeeding
- Women who have had an abortion
- Women with a BMI >30
- Women with HIV
- Women with diabetes
- Women with migraine +/- aura
- Women with contraindication to oestrogens

[Click here for references](#)

### Copper IUD

**99.7%**

Efficient

Duration 5–10 years

Reversible  
immediately

### IUS

**99.7%**

Efficient

Duration 5 years

Reversible  
immediately

### Injectable

**99.8%**

Efficient

Duration  
12 weeks

Reversible  
up to one year

### Implant

**99.9%**

Efficient

Duration 3 years

Reversible  
immediately

**!** Please check summary of product characteristics for specific drug information

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“A 30-minute video explores why HCPs should talk to patients about sex and sexual difficulties and how these discussions can improve a person’s quality of life.”

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# 14 Top tips when dealing with sexual difficulties

## Ways of asking

'I realise this is a very personal subject...'

'Some people with MS find...'

'You may not wish to discuss it at the moment, but if you do you can contact...'

'Here is a booklet which you may find useful; happy to discuss anything if you want to...'

'Encourage patients to have a sense of humour about it if possible.'

'Sex doesn't have to include orgasm.'

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## Resources

These resources focus on different aspects of sex and disability. We cannot take responsibility for the content of websites but we have tried to identify some of the most informative or practical.

### Films

- **The Sessions** (2012)  
A man with an iron lung/polio, who wishes to lose his virginity, contacts a professional sex surrogate with the help of his therapist and priest.
- **Inside I'm Dancing** (2004)  
The story of two young disabled men's fight for independent living and their confusion when they fall in love with the same carer.
- **Untouchable** (2011)  
The story of a quadriplegic and his carer, who encourages him to pursue love. A true story, the friendship between the two men develops after the millionaire's paragliding accident. The Senegal-born ex-convict becomes his carer despite stealing a Fabergé egg during his job interview, and the pair are drawn together by honesty and humour, fear and friendship.
- **Rust and Bone** (2012)  
Won the top prize at the London Film Festival. A woman comes to the conclusion that no man will want her sexually after she loses both legs in an accident — until she reconnects with the very physical fighter played by Matthias Schoenaerts, who treats her like any other woman.

- **Scarlet Road** (2011)  
Documentary which follows the extraordinary work of Australian sex worker, Rachel Wotton. Impassioned about freedom of sexual expression and the rights of sex workers, she specialises in a long over-looked clientèle - people with disability.
- **Secretary** (2002)  
A young woman, recently released from a mental hospital, gets a job as a secretary to a demanding lawyer, where their employer-employee relationship turns into a sexual, sadomasochistic one.

### Documentaries/TV shows

- Channel 4, though they like to use sensational titles, have quite a lot of documentaries on sex and on sex and disability.
- **The Sex Education Show**  
Available on Channel 4OD
  - **Undateables**  
Available on Channel 4OD, showing the journey of different individual's with physical and learning disabilities as they try to find a relationship.
  - **40-Year-Old Virgins**  
Available on Channel 4OD, this is not about disability, but can be helpful watching to those who have not had much sexual experience. It shows the journey of a man and a woman who have not had sex before because of negative

experiences. They travel to the US to visit a sex surrogate to help them get over their fear of sex and help them explore their sexual selves.

- **Virgin School**  
Available on Channel 4OD, this explores the journey of a shy man who found it difficult to date and have sex with girls. He visits a sex surrogate school in the Netherlands where he embarks on a journey of self-discovery.
- **Desperate Virgins**  
Available on Channel 4OD.

### Books

- **Sex and Disability – A Guide to Everyday Practice**  
by Morgan Williams
- **An intimate life. Sex, love and my journey as a surrogate partner**  
by Cheryl T. Cohen Greene with Lorna Garano.
- **Dare**  
by Tracey Cox. Twenty couples explore fantasy. How some of them manage to safely enact their fantasies.
- **The Ultimate Guide to Sex and Disability**  
by Miriam Kaufman: A self-help sex guide for people living with disabilities, chronic pain and illness.
- **Desires**  
by Penny Pepper: erotic stories involving people with disabilities.

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- **The Body Image Workbook**

by Thomas Cash

- **Tactile Mind**

by Lisa Murphy:

nude photographs for the blind, available from [www.tactilemindbook.com](http://www.tactilemindbook.com)

- **The New Joy of Sex**

by Susan Quilliam: written by a disability informed author.

- **Becoming Orgasmic**

by J Heiman: highly recommended for women by psychosexual therapists.

- **The Sex Book**

by Suzi Godson, Mel Agace, Robert Winston Cassell: explores the subject of sex, health and sexuality in a straightforward and adventurous way.

- **Enabling romance: A guide to love, sex and relationships for people with disabilities (and the people who care about them)**

by Ken Kroll and Erica Levy Klein: this book covers sexual stereotypes, building self-esteem, reproduction, and sexuality for people with disabilities and their partners.

- **My Secret Garden**

by Nancy Friday: compilation of women's fantasies.

- **How I Became a Human Being: A Disabled Man's Quest for Independence**

by Mark O'Brien with Gillian Kendall

## Booklets by MS organisations

### MS Trust Booklet: Sexuality and MS: a guide for women

by Nicki Ward Abel and Janice Sykes.

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

### MS Trust Booklet: Sex and MS: a guide for men

by Simon Webster.

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

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

### MS Society Canada: Intimacy and Sexuality in MS

[www.mssociety.ca](http://www.mssociety.ca)

### MS Society Essentials Guide No 12: Sex, Intimacy and relationships.

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

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## Support for people with disabilities

Increasing amounts of support are available for people with disabilities who want to be sexually active but may need support.

### Spokz People

Non-profit arm of Spokz provides UK-wide disability counselling, including sex and relationship support, by telephone, online and in some areas, through groups for people with physical disabilities, their partners and health professionals.

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

### Enhance the UK

Enhance the UK is a charity helping people with a disability to play a full and active role in society. It runs the Undressing Disability Campaign and The Love Lounge. It works with Brook to make sure young disabled people have access to the same sex education and sexual health services, advice and support as their peers. The Love Lounge is an online area to ask experts about sex and disability including advice, dating, meeting people, coming out as gay.

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

### Shada

Sexual Health and Disability Alliance was formed in 2005 by the Outsiders Trust to bring together professionals working with disabled people who may be struggling to support them express themselves sexually. It provides information on sex and disability and runs meetings twice a year for disabled people and professionals.

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

### Outsiders

Outsiders offers support and expertise on disability, relationships and sexuality. It runs a private club for socially and physically disabled people, where members offer each other peer support and friendship and many find love and happiness. It organises lunches for members around the country. It runs the Sex and Disability Helpline, the Sexual Health and Disability Alliance for health and social care professionals, a sexual advocacy services and an online resource, the Sexual Respect Tool Kit. Outsiders campaigns for disabled people to be accepted as sexual and to receive good sex and disability education. Administration, projects and funding are handled by the Outsiders Trust, a registered charity.

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

### The Site

The Site is the online guide to life for 16-25 year-olds in the UK. It provides non-judgmental support and information on everything from sex and exam stress to debt and drugs. It is not specifically for people with disabilities but has a comprehensive section on sex and relationships.

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

## Dating sites for people with disabilities

### LINKS

Online dating with disability [www.theguardian.com](http://www.theguardian.com)

Specialist disabled dating  
[www.disabilitymatch.co.uk](http://www.disabilitymatch.co.uk)

Disabled dating websites  
[www.disableddatingclub.org](http://www.disableddatingclub.org)  
[www.disableddatingchums.com](http://www.disableddatingchums.com)

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## Sex education

### Channel Four – Sexperience

Videos and information on different aspects of sex and the human anatomy featuring real people and health professionals. Not specifically aimed at people with disabilities.

[www.sexperienceuk.channel4.com](http://www.sexperienceuk.channel4.com)

### Leonard Cheshire Disability

The charity's project In Touch gave young disabled people greater access to sexual health services and information. Many of the project resources are still available online including films and training resources.

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

### Disability Horizons

Disability Horizons magazine is the UK's fastest growing disability lifestyle publication. Started by two disabled entrepreneurs in the summer of 2011, Disability Horizons has a rapidly growing monthly web audience of 25,000 people. The magazine's content is sourced entirely from its reader community. There is a well resourced section on relationships and sex.

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

## Professional development

### The Sexual Respect Toolkit

For GPs and other health and social care professionals to feel more comfortable initiating discussions about sex. A 30-minute video explores why HCPs should talk to patients about sex and sexual difficulties and how these discussions can improve a person's quality of life. Video features Alex Cowan and sexuality from her perspective. Interview with a disabled man who has had support from a sex therapist. The Toolkit is produced by the Outsiders Trust.

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

### Institute of Psychosexual Medicine

A registered charity which provides education, training and research in psychosexual medicine. Trained doctors can help people with a wide range of sexual difficulties. Sex specialists are listed by area on the website.

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

### Shada

Sexual Health and Disability Alliance was formed in 2005 by the Outsiders Trust to bring together professionals working with disabled people who may be struggling to support them express themselves sexually. It provides information on sex and disability and runs meetings twice a year for disabled people and professionals.

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

### Warrington Disability Partnership

Warrington Disability Partnership (WDP) is an independent, user led Social Enterprise committed to positive change and independent living. It runs a helpline about sex and disability and sex workshops for health, social care and educational support professionals.

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

### The TLC Trust

The TLC Trust provides advice and support to disabled men and women so they can find appropriate sexual and therapeutic services. Its website lists sex workers, surrogates, striptease artists, body workers and tantric teachers. It offers information and advice to professionals on disability and the law on booking sexual services. It promotes the sexual rights of disabled people and campaigns for laws that enable disabled people to hire sexual services.

[www.tlc-trust.org.uk](http://www.tlc-trust.org.uk)

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## Counselling and therapy

### Axis Counselling

Based in Shropshire, the company offers counselling for adult survivors of childhood sexual, physical or emotional abuse.

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

### South London and Maudsley Psychosexual Service

Focused on promoting mental health and well-being, it has a psychosexual referral service.

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

### NHS sexual health website

General advice on sexual health but nothing specifically related to sex and MS.

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

### IAPT Service Directory - NHS services for depression and anxiety

The Improving Access to Psychological Therapies (IAPT) programme supports the NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety. It lists services by region.

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

### College of Sexual and Relationship Therapists

Membership organisation for therapists specialising in sexual and relationship issues. Runs a directory that can be searched by name, area and postcode.

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

### British Association for Sexual and Marital Therapy

The website covers many different topics including sex and disability.

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

### RELATE

Leading relationship counselling organisation offering specific help for people having problems with sex.

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

### Forums – share with peers

#### Apparelyzed

A spinal cord injury peer support website run by individuals with spinal cord injuries. Patients can sign up to view sex and relationship posts.

<http://www.apparelyzed.com>

#### Youareable

Online community of disabled people.

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

### Sex aids

#### Spokz

A range of sex aids to help people with mobility, dexterity and sensation issues.

Includes masturbation aids for men and women, sex furniture and cushions, lubricants, massage oils and more. Spokz was set up to enhance the lives of people with disabilities through lifestyle, leisure and sports products and services aimed at enhancing physical, mental and sexual wellbeing.

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

### Come as you are

A worker-owned co-operative sex shop. Explains how to adapt sex toys and has a range of sex and disability links.

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

### Ann Summers

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

0845 456 6948

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

### Beecourse

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

01264 358853

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

### Love Honey

Website and mail-order catalogue.

0800 915 6635

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

### Sh!

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

0845 868 9599

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

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## Did you know?

The average shelf-life of a latex condom is **2 years**

**1%** of adult females are able to achieve orgasm solely through breast stimulation

Cherry is the most popular flavour of edible underwear



Men have **4–5** erections each night when they are asleep

A woman's nipples can swell up to **25%** their normal size when aroused

The average bout of sexual intercourse burns **360 calories** per hour



The male orgasm lasts **5 seconds**  
The female orgasm lasts **10–15 seconds** or more

The first vibrators were invented in 1869 as treatment for 'hysteria'



The left testicle usually hangs lower than the right for right-handed men

The clitoris is the only human organ whose single purpose is to provide pleasure

It takes a sperm **1 hour** to swim **7 inches**



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