

Symptoms, effects and management

Sexuality

NICE guidelines¹ state that MS may disturb the normal sexual physiology and may result in other impairments that make normal sexual behavior difficult. This may make it difficult for the person to establish or maintain relationships and as both aspects are important they should be recognized together.

Epidemiology

Sexual problems are common in multiple sclerosis. Estimates of the frequency of dysfunctions vary. Lilius et al² found that 91% of male respondents to a postal questionnaire had experienced a change in their sex lives with 64% describing an unsatisfactory or inactive sex life. In addition 72% of women in the study reported a change with 39% experiencing an unsatisfactory or inactive sex life. Such reports tend to focus on physical problems and the total impact of a change in an individual's sexuality is often overlooked.

Sexual dysfunction correlates positively with the presence of other disabilities in particular bladder and bowel symptoms, sensory disturbance of the genitalia, weakness of the pelvic floor and spasticity^{3,4}. The associated factors may be recognised as 'risk factors' and alert health professionals to the possibility of sexual dysfunction. In common with these other symptoms of MS those of sexual dysfunction too can relapse and remit. Studies have estimated that over 50% of people with neurological disorders may experience sexual dysfunction, but approximately 25% express concern about their difficulty and these are the people who may require help^{5,6}. People do not always voice their concerns in this area but the NICE guidelines¹ recognise the importance of enjoying sexual health regardless of illness or disability and state, 'Every person (or couple) with MS should be asked sensitively about or given opportunity to remark upon, any difficulties they may be having in establishing sexual or personal relationships'.

Types of Dysfunction

Kaplan⁷ divided the sexual response cycle into three phases – desire, excitement and orgasm.

Sexual problems can be described as primary, secondary or tertiary⁸. People with MS may experience dysfunctions at any of these phases. Primary dysfunction is caused directly by demyelination, for example numbness in the genital area. Secondary sexual dysfunction occurs as a result of MS symptoms such as spasticity, and tertiary dysfunction can be seen as a result of the psychosocial impact such as depression or changes within the relationship. It is important to establish in which of these areas the sexual problem is presenting.

Medication commonly contributes to sexual dysfunction; for example, tricyclic anti-depressants are associated with erectile dysfunction and the selective serotonin reuptake inhibitors are associated with delayed or absent orgasm or ejaculation. Loss of desire may result from depression or changes within the dynamics of the relationship. People should be offered information about locally available counselling and supportive services such as Relate. If all else fails psychosexual counselling may be considered.

The very nature of sexual problems can make discussion difficult for both people with MS and healthcare professionals. Individuals may not be aware that MS can affect sexual functioning and assessment of these needs is important.

Men with MS

The commonest dysfunction in the excitement phase is erectile dysfunction. This is often a primary symptom, a direct result of demyelination though it is important in the assessment to explore both psychosexual and relationship factors as well as the physical aetiology. The cause of sexual dysfunction is often multifactorial.

Oral medications are the most popular first line treatment and are probably effective in 70-80% of men. Their safety have been evaluated in large-scale clinical trials; with more than 4000 patients worldwide (with a range of underlying pathology) at doses of 25mg, 50mg and 100mg there was evidence of improvement in both frequency of penetration and maintenance of erection. NICE guidance¹ recommends that men with persisting erectile dysfunction who do not have contraindications should be offered 25 – 100 mg sildenafil (Viagra).

Side effects most commonly mentioned are headache, flushing, rhinitis (nasal congestion) and dyspepsia. The only absolute contraindication to sildenafil is concurrent nitrate therapy. Apomorphine hydrochloride (Uprima) is another pharmacological development that is now also being marketed as treatment for male erectile dysfunction. The recommended starting dose is 2mg, which can be increased to 3mg or 4mg under supervision. Tadalafil (Cialis) 10mg or 20mg is now also available and has the advantage of being able to last for 24 hours. Where someone

does not respond to sildenafil they should be assessed for general and specific factors that might worsen erectile dysfunction; these might include depression, anxiety, vascular disease, diabetes and other medications. Treatments such as alprostadil or intra cavernosal papaverine could then be considered, or intraurethral applications (eg MUSE), or a constriction ring. Vacuum devices are now rarely used but may be preferred by some older men.

Medications will not on their own solve psychological or relationship issues, but can be helpful in conjunction with counselling.

Women with MS

Most of our knowledge regarding sexual functioning has been derived from studies in men. Understanding of female sexual dysfunction is gradually increasing in what has previously been a neglected area.

Problems may include loss of libido, lack of vaginal lubrication, difficulty in achieving orgasm, pain during intercourse and numbness. Although, as with men, psychological factors certainly may play a role, it seems that a component of the sexual dysfunction has a neurological basis.

Women may experience alteration in the excitement phase and work is being carried out in this area, however trials have found that sildenafil is not effective in women⁹. There have not been many advances in the therapeutic options, with reliance on topical lubricants and creams. Poor vaginal lubrication can

easily be solved by liberal application of waterbased lubricants such as K-Y jelly.

Changed sensation in the genital area may respond to treatment such as carbamazepine or amitriptyline. Some women find that the use of vibrators and other sexual aids increases the intensity of stimulation. Education can also be important in helping women to explore other means of achieving orgasm and additional erogenous zones¹⁰. Partners could experiment to find new ways to approach altered sexual functioning and not lose sight of the fact that this can be fun.

Partners and Relationships

Masters and Johnson¹¹ observed that there is no such thing as an uninvolved partner. The turmoil of emotions, which may occur in response to the onset of disability, impacts upon the partner and may alter their need for autonomy and intimacy. A change in roles within a relationship from an equal partnership to one of 'carer' and 'cared for' substantially alters the dynamics of the relationship. In addition the effects of cognitive changes on the relationship may need to be addressed. Some couples may adjust and adapt to a new type of relationship but others may experience great distress. Identified risk factors within relationships are the presence of a progressive condition, marriages begun before the onset of disability and the presence of a sexual dysfunction^{6,12,13,14}. The importance of intimacy, and communication within couples is vital as people often have difficulty talking about problems with each other.

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Being Single

Sexual expression is no less of an issue for those not currently in a relationship. Often there is a greater degree of reticence about asking for help. Concerns about sexual functioning with a new partner, or about finding a partner in the face of mobility problems, continence difficulties and so on, need the opportunity to be voiced.

Helping individuals and couples with sexual and / or relationship difficulties

A commonly used model in facilitating discussion of sexual dysfunction is known as the P-LI-SS-IT model. This is a hierarchical model that can be applied by any health care professional to the point at which they feel able to operate¹⁵. The components of the acronym are pyramidal; many people will benefit from the first intervention but few from the fourth.

P – giving people permission to discuss sex and relationship worries. Professionals should be able to pick up cues or ask specifically about sex and relationship issues. “MS can have quite an effect on the more intimate side of life. Has that caused you any concern?”

LI – providing limited information about any areas of concern. This can be done by whoever the person with MS has confided in. If they feel unable to provide information, then having listened to the problem they can make a referral to another agency such as a sexual dysfunction clinic, counselling or Relate.

Acknowledgement of the problem and empowerment to look further for help is very important.

SS – providing specific suggestions, for example about how to manage continence problems to allow sexual intimacy, managing fatigue, positioning to avoid spasm or pain. Many of these suggestions are made most appropriately by a professional with knowledge of neurological problems rather than just skill in treating sexual dysfunction.

IT – intensive therapy. Specialised psychosexual therapy. The majority of problems can be dealt with earlier in this model.

All health care professionals can undertake the first step in the PLISSIT model providing they are prepared to listen. This alone can be of immense therapeutic benefit.

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Further Reading Publications from the MS Trust*

▶ For people with MS

MS: what does it mean for me? - For people newly diagnosed with MS, a practical introduction to MS to help answer questions at a time of uncertainty.

MS together - A DVD that offers clear and concise information on MS.

Disease modifying drug therapies - A general guide to people with MS that covers disease modifying drug therapies licensed for use in the UK.

At work with MS: managing life and work - Elements that make for a successful working life when someone has MS and considers the support available to both the person with MS and the employer.

Living with fatigue - Offers advice on how to live with fatigue, one of the commonest symptoms of MS.

MS Explained - A guide to the mechanisms of the disease.

Sexuality and MS - a guide for women - Explains how MS can impact on sexuality and intimacy and offers positive practical solutions.

Young person's guide to MS - For young people aged 10-15 who have a parent with MS.

Exercises for people with MS - Exercises from a senior physiotherapist illustrated throughout by easy to follow diagrams and on DVD in **Move it for MS**.

Move it for MS - A DVD of exercises for people with MS.

Factsheets covering a wide range of symptoms and therapies - for further details and to order any of the publications contact the MS Trust Information team 01476 476 700 email infoteam@mstrust.org.uk.

▶ For health and social care professionals

Spasticity care pathway - The role of the nurse in the management of spasticity

Therapists in MS: delivering the long-term solutions

Comprehensive resources are available to download from our website www.mstrust.org.uk.

* As of November 2007

Publications

We hope that you have found this information helpful. The MS Trust offers a wide range of publications, including our quarterly newsletter Way Ahead and the MS Information Update. These provide details of latest developments and recently published papers in the field of MS. Our website is regularly updated www.mstrust.org.uk

Contact us to receive our newsletter or to request another publication. All our services are free within the UK.

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Publications

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