



# Multiple sclerosis information

---

## for health and social care professionals

MS: an overview

Diagnosis

Types of MS

Prognosis

Clinical measures

A multidisciplinary approach to MS care

Self-management

Relapse and drug therapies

Relapse

Steroids

Disease modifying drug therapies

Symptoms, effects and management

Vision

Fatigue

Cognition

Depression

Women's health

Bladder

Bowel

Sexuality

Mobility

Spasticity

Tremor

Pain

Communication and swallowing

Pressure ulcers

Advanced MS

Complementary and alternative medicine

Index

## Sexuality

The NICE clinical guideline<sup>1</sup> states that MS may disturb the normal sexual physiology and may result in other impairments that make normal sexual behaviour difficult. This may make it difficult for the person to establish or maintain relationships and as both aspects are important they should be recognised together.

## Epidemiology

Sexual problems are common in multiple sclerosis. Estimates of the frequency of sexual dysfunctions vary from 50 to 90% in men and 40 to 80% in women, depending on the severity of disability of the group and duration of illness<sup>2-5</sup>. 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<sup>6-8</sup>. The associated factors may be recognised as 'risk factors' and alert health professionals to the possibility of sexual dysfunction. In common with other symptoms of MS those of sexual dysfunction can also relapse and remit. Studies have estimated that over 50% of people with neurological disorders may experience sexual dysfunction, but only approximately 25% express concern about problems they may have<sup>9,10</sup>. People do not always voice their concerns and health professionals are sometimes reluctant to enquire but people with MS should be offered the opportunity to discuss any issues or problems. The NICE clinical guideline<sup>1</sup> recognises the importance of enjoying sexual health regardless of illness or disability and states, '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

Kaplan<sup>11</sup> divided the sexual response cycle into three phases - desire, excitement and orgasm.

Sexual problems can be described as primary, secondary or tertiary<sup>2</sup>. People with MS may experience dysfunctions as a consequence of one or all of the above. 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 antidepressants 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. Psychosexual counselling may be appropriate for some.

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 which brings a significant impact on quality of life<sup>3,12</sup>. This is often a primary symptom, a direct result of demyelination. However, assessment must include psychosexual and relationship factors as well as the physical aetiology since the cause of sexual dysfunction is often multifactorial. Erectile dysfunction may also be the first sign of cardiovascular disease<sup>13</sup>.

The PDE5 inhibitors, sildenafil (Viagra), vardenafil (Levitra) and tadalafil (Cialis) are the most popular first line treatments and are probably effective in 70-80% of men. A double-blind, randomised trial involving 217 men with MS found that sildenafil significantly improved erections (90% of patients) compared with placebo (24% of patients)<sup>14</sup>. NICE guidance<sup>1</sup> recommends that men with persisting erectile dysfunction who do not have contraindications should be offered 25-100mg sildenafil.

Tadalafil has the advantage of being effective for up to 36 hours which may mean less planning and pressure to have sexual intercourse to a schedule. In an Italian study, 72 of 92 (78%) men with MS responded to 10-20mg doses of tadalafil, with statistically significant improvements in erectile function and in sexual satisfaction scores<sup>15</sup>.

# Symptoms, effects and management

## Sexuality

Side effects most commonly experienced with PDE5 inhibitors include headache, flushing, rhinitis (nasal congestion) and dyspepsia. The only absolute contraindication to PDE5 inhibitors is concurrent nitrate therapy and nicorandil.

Where someone does not respond to PDE5 inhibitors 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. Alternative treatments such as alprostadil or intra cavernosal papaverine could then be considered, or intraurethral applications (eg MUSE), or a constriction ring. Vacuum devices are excellent at preventing penile atrophy and should be considered as an adjunct to pharmacological management.

Medications may 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. As with men, both psychological and neurological factors are components of sexual dysfunction.

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 women<sup>16</sup>. 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 water-based lubricants such as Sylk or Senselle.

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 zones. Partners could be encouraged to 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 Johnson<sup>17</sup> 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, relationships begun before the onset of disability and the presence of a sexual dysfunction<sup>10,18-20</sup>. The importance of intimacy and communication within couples is vital as people often have difficulty talking about problems with each other.

### People who are not in a relationship

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 and other difficulties, 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-SSIT model. This is a hierarchical model that can be applied by any health professional to the point at which they feel able to operate<sup>21,22</sup>. 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 P-LI-SS-IT model providing they are prepared to listen. This alone can be of immense therapeutic benefit.

### References

1. National Institute for Health and Clinical Excellence. Multiple sclerosis - management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8. London: NICE; 2003.
2. Foley FW, Sanders A. Sexuality, multiple sclerosis and women. Mult Scler Management 1997;4(1):3-9.
3. Tepavcevic D, Kostic J, Basuroski I, et al. The impact of sexual dysfunction on the quality of life measured by MSQoL-54 in patients with multiple sclerosis. Mult Scler 2008;14(8):1131-6.
4. Zorzon M, Zivadinov R, Monti Bragadin L, et al. Sexual dysfunction in multiple sclerosis: a 2-year follow-up study. J Neurol Sci 2001;187(1-2):1-5.
5. Demirkiran M, Sarica Y, Uguz S, et al. Multiple sclerosis patients with and without sexual dysfunction: are there any differences? Mult Scler 2006;12(2):209-14.
6. Hulter BM, Lundberg PO. Sexual function in women with advanced multiple sclerosis. J Neurol Neurosurg Psychiatry 1995;59(1):83-6.
7. Vas CJ. Sexual impotence and some autonomic disturbances in men with multiple sclerosis. Acta Neurol Scand 1969;45(2):166-82.
8. Fraser C, Mahoney J, McGurl J. Correlates of sexual dysfunction in men and women with multiple sclerosis. J Neurosci Nurs 2008;40(5):312-7.
9. Szasz G, Paty D, Maurice WL. Sexual dysfunctions in multiple sclerosis. Ann NY Acad Sci 1984;436:443-52.
10. Chandler BJ, Brown S. Sex and relationship dysfunction in neurological disability. J Neurol Neurosurg Psychiatry 1998;65(6):877-80.
11. Kaplan HS. The new sex therapy: active treatment of sexual dysfunction. New York: Brunner/Mazel; 1974.
12. Zorzon M, Zivadinov R, Bosco A, et al. Sexual dysfunction in multiple sclerosis: a case-control study. I. Frequency and comparison of groups. Mult Scler 1999;5(6):418-27.
13. Kirby M, Jackson G, Betteridge J, et al. Is erectile dysfunction a marker for cardiovascular disease? Int J Clin Pract 2001;55(9):614-8.
14. Fowler CJ, Miller JR, Sharief MK, et al. A double blind, randomised study of sildenafil citrate for erectile dysfunction in men with multiple sclerosis. J Neurol Neurosurg Psychiatry 2005;76(5):700-5.
15. Lombardi G, Macchiarella A, Del Popolo G. Efficacy and safety of tadalafil for erectile dysfunction in patients with multiple sclerosis. J Sex Med. 2010;7(6):2192-200.
16. DasGupta R, Wiseman OJ, Kanabar G, et al. Efficacy of sildenafil in the treatment of female sexual dysfunction due to multiple sclerosis. J Urol 2004;171(3):1189-93.
17. Masters WH, Johnson VE. Human sexual response. London: J & Churchill Ltd; 1966.
18. Halvorsen JG, Metz ME. Sexual dysfunction, part 1: Classification, etiology and pathogenesis. J Am Board Fam Pract 1992;5(1):51-61.
19. Abrams KS. The impact on marriages of adult-onset paraplegia. Paraplegia 1981;19(4):253-9.
20. Woollett SL, Edelmann RJ. Marital satisfaction in individuals with multiple sclerosis and their partners; the interactive effect of life satisfaction, social networks and disability. Sex Marital Therapy 1988;3(2):191-6.
21. Annon JS. The behavioural treatment of sexual problems: brief therapy. New York: Harper and Row; 1976.
22. Taylor B, Davis S. Using the extended PLISSIT model to address sexual healthcare needs. Nurs Stand 2006 21(11): 35-40.

### MS Trust resources

MS and sex: a guide for men



MS and sexuality: a guide for women

### Further resources

Kessler TM, Fowler CJ, Panicker JN. Sexual dysfunction in multiple sclerosis. Expert Rev Neurother 2009;9(3):341-50.

Fletcher SG, Castro-Borrero W, Remington G, et al. Sexual dysfunction in patients with multiple sclerosis: a multidisciplinary approach to evaluation and management. Nat Clin Pract Urol 2009;6(2):96-107.

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

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

## MS Trust information service

### Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

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



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

email infoteam@mstrust.org.uk

write MS Trust  
Spirella Building  
Letchworth Garden City  
SG6 4ET



This publication will be reviewed in three years

MS Trust  
Multiple sclerosis information for health and social care professionals. Fourth edition.  
ISBN 1-904 156-24-X  
© 2011 Multiple Sclerosis Trust

Registered charity no. 1088353

All rights reserved. No part of this book may be produced, stored in a retrieval system or transmitted in any form by any means, electronic, electrostatic, magnetic tape, mechanical, photocopying, recording or otherwise without written permission of the publisher.