A paper funded by the Multiple Sclerosis Society and published in the International Journal of MS Care in 1999, looked at the obstacles facing MS Societies in helping their clientele deal with issues to do with sexual dysfunction.

The authors ([1]) found that over 70% of man and women with MS experience sexual dysfunction, and they claimed it to be more common in MS than in any other chronic illness.

Sexual problems can be divided into: *primary*, *secondary* and *tertiary*:

- <u>Primary:</u> physiological impairment i.e. physical problems directly relating to specific damage.

- <u>Secondary</u>: non-sexual (indirect) physical impairment: e.g. fatigue, pain, spasticity (increased muscle tone and maybe spasms), bladder and bowel dysfunction

- <u>*Tertiary*</u>: psychological and sociocultural issues: low self-esteem, demoralisation, depression, interpersonal/communication difficulties.

The 1999 paper found that there were 6 themes and key ideas identified through interviews with MS Society staff and focus groups:

1. Most MS staff are uncomfortable in discussing issues relating to sexual dysfunction

2. Healthcare professional, MS Society staff and MS clients have insufficient knowledge about sexual dysfunction due to MS. This was felt to constitute a major obstacle.

3. There is a lack of local resources

4. *Various obstacles prevent effective communication:* predominantly sociocultural issues; many people find any discussion on the topic of sex to be extremely difficult.

5. *The effect of sexual dysfunction on partners is overlooked:* this puts further stress on the patient-caregiver relationship.

6. There is a need for local cultural factors to be considered

These factors are just as applicable to arachnoiditis.

The suggested solutions in the paper were based around establishing an Intimacy/sexuality (IS) liaison person at each Society; this individual could gather and pass on educational material, assess the needs of those clients who wish for help with this type of problem, identifies local resources and implements an educational/ supportive programme for clients/members and other Society staff.

Some of the sexual difficulties experienced by MSers include:

- Temporary or long-term reduction in libido (commonest complaint)
- Inability to achieve orgasm
- Difficulty in engaging in intercourse
- Inability to achieve/maintain an erection

Women with MS tend to report changed sensation in the genital area, reduced vaginal lubrication and difficulty achieving arousal. Studies seem to suggest that the level of sexual dysfunction is proportionate to the level of disability.

As with arachnoiditis, it can be difficult to ascertain whether the disease process of MS itself is solely the cause, or to what extent other factors such as fatigue and pain or medication may be involved.

Primary sexual dysfunction due to direct physical impairment such as loss of sensation may be difficult to treat especially if there is loss of sexual desire.

In healthy individuals, sexual arousal tends to be a dynamic process involving both mental and physical arousal, the one encouraging the other and vice versa, so to speak.

If the physical arousal does not occur, or is not detectable (vaginal lubrication may be normal even if sensation is lost...see below) then a vital part of the process is absent.

When loss of desire is due to secondary factors such as fatigue, or tertiary factors such as depression, then these symptoms may be treatable or may be made manageable.

Some women report that they can compensate for loss of sexual desire by initiating sexual activities without feeling desire, and are able to attain sexual pleasure with sufficient emotional and physical stimulation.

It requires establishing a new set of signals as indicators for sexual behaviour and subsequent sexual enjoyment.

Measures such as spending time on sensual experiences (warm bath, candle-light, music) sounds corny, but may be very helpful in setting the ?mood', and above all, closeness with a partner, emotionally speaking. (in relationships which are strained by the daily stresses of coping with chronic illness, this may be rather difficult to achieve, but is all the more necessary for that very reason).

It is all about teaching ourselves new ways in which to rekindle sexual desire in the absence of the physical sensations which used to serve as powerful stimuli to heighten sexual desire.

[1] Foley FW, Poster C, Sheridan P, Brown B, Hatch J and McDonald E International Journal of MS Care September 1999, Qualitative Evaluation of Obstacles Facing Multiple Sclerosis Societies in Addressing Sexual Dysfunction *in MS.*