Multiple
Sclerosis
Trust
MS

Multiple sclerosis information

for health and social care professionals

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Fourth Edition

Women's health

Women with MS outnumber men by 3:1[1] and disease activity appears related to hormonal fluctuations by as yet, poorly understood mechanisms. Hence there are special considerations that need to be taken into account for women with MS, and the health professional requires an understanding of the impact of menstruation, pregnancy and menopause on MS.

Menstruation

Many women report cyclical changes in MS symptoms and feel that their symptoms deteriorate two to three days prior to the onset of their menstrual period and improve once bleeding has started. A few small studies have confirmed this anecdotal evidence though more work undoubtedly needs to be done in this area[2-4].

In one small study[5] it was found that 78% of women had premenstrual worsening of their MS symptoms in one or more of the menstrual cycles analysed. Symptoms most likely to increase pre-menstrually were limb weakness, pain and nocturia. Additionally, another small scale study found that those on combined oral contraception reported that their MS symptoms worsened during the pill-free week[6]. A greater understanding of this 'menstrual cycle effect' by women with MS and health professionals would help to reduce anxiety associated with an unexpected increase in symptoms.

Current data suggests that premenstrual symptoms alone cannot account for the change in MS symptoms and other hormonally related factors may be important. It is tempting to assume that the decline in the level of oestrogens accounts for premenstrual deterioration in MS symptoms. Research into MS and pregnancy[7,8] points to oestrogen having a protective effect as it may suppress autoimmunity. Unfortunately solutions are rarely simple and an obvious question that comes to mind is "if oestrogen is so beneficial, why do more women than men have MS?" Sadly this paradox is still to be solved.

Women who are disabled by MS and who are no longer contemplating having children may want to consider ceasing menstruation by hormonal means. They should be encouraged to explore available options with their GP or practice nurse. Adopting this strategy may benefit carers particularly where a male is looking after a female partner and the couple find this aspect of care particularly difficult to deal with.

Contraception

All forms of birth control are available for people with MS, although various factors should be taken into account when decisions about contraception are being made. These include patient choice, ease, comfort, effectiveness, interaction with medications, and physical limitations such as loss of dexterity or spasticity.

There are no contraindications specific to women with MS for oral contraceptives, although it is recommended[9] that there should be discussion with a physician since certain drugs, including antibiotics, phenytoin and carbamazepine, may reduce oral contraceptive effectiveness. It should be borne in mind that there is an increased risk of thrombosis associated with immobility, and the usual checks on weight, smoking and so on should be made as for any other woman contemplating oral contraceptives. If cognitive impairment affects the woman's ability to take daily oral contraceptives reliably, then a transdermal weekly patch may be a good alternative.

Good manual dexterity is needed for the use of barrier contraceptives, such as diaphragm, condoms and spermicides; hand tremor, weakness or sensory loss could therefore be problematic. It may be prudent to inform women with MS that using a diaphragm may increase the likelihood of bladder infections.

Intrauterine devices (IUD) have been shown to be generally safe, effective and easy to use. Hormone-releasing IUDs (eg Mirena coil) have the advantage of reducing menstrual flow and duration[10].

Another option is a progesterone implant, again requiring no maintenance and effective for up to five years. Progesterone can also be injected on a three monthly basis.

Pregnancy

Because MS is most commonly diagnosed in women aged between mid 20s and early 30s, the question of pregnancy is an important one. The main issues are: the effect of the pregnancy on the mother with MS, the overall outcome of the pregnancy in terms of the baby's health, and the risk that the baby will inherit MS. A study investigating the concerns of pregnant women with MS[11] identified labour, delivery issues, breast feeding and short and long-term parenting issues. The unpredictability of MS resulting in uncertainty permeated many of these concerns.

Effect of pregnancy on the mother with MS

Until 1950 and the publication of Tillman's paper[12] on the effect of pregnancy on MS and its management, women with MS were advised to avoid pregnancy. Since 1950, many researchers in both retrospective and prospective studies have borne out Tillman's findings that pregnancy has no long-term effect on disability. However, there are still many myths and misconceptions about MS and pregnancy and some people (including health professionals) express disapproval when a woman with MS becomes pregnant.

In common with many other autoimmune diseases (rheumatoid arthritis, myasthenia gravis, for example), fewer disease events may be experienced during pregnancy for women with relapsing remitting MS, especially during the third trimester. This suggests that there is some protection from pregnancy-related hormones. However, that protection does not seem to apply to women with progressive disease. During the three months postpartum the risk of a relapse increases. Overall, however, pregnancy does not affect disease outcome or level of disability, and a two year follow up study determined that birth relapse risk is similar to that in the pre-pregnancy year[13]. While one small scale study suggested that breast feeding may offer a degree of protection against postpartum relapse[14], a second, larger study found that breast feeding did not reduce the relapse rate post delivery[15].

NICE guidance states that women with MS should be offered the most appropriate analgesia for them during delivery. Concerns are sometimes expressed regarding the use of epidural anaesthesia, but there is no evidence that epidural administration of drugs has any effect on relapse rate or disability[16].

The incidence of instrumental or caesarean section deliveries has been shown to be no higher for women with MS. Although a small study concluded that women with MS were more likely to have assisted vaginal deliveries than those without[17], a larger scale Canadian study refuted these findings[18].

Overall outcome of the pregnancy in terms of the baby's health

There is no increased risk of miscarriage, foetal malformations, stillbirths, birth defects or infant mortality when the mother has MS.

Risk that the baby will inherit MS

MS is not hereditary and the majority of people who develop MS have no previous family history of the condition. However, family studies have revealed that there is a higher, but still small, risk of developing MS for someone with a relative with the condition[19]. In the general population in the UK, the risk of developing MS is about 1 in 700. The risk is higher for people who already have someone with MS in their family. On average, the risk for first degree relatives (parents, children, siblings) of someone with MS is about 1 in 40. For second degree relatives (cousins, uncles/aunts, nephews/nieces) it is around 1 in 100. While there is a genetic predisposition to MS, the actual risk is considered low and should not deter a couple from starting a family.

Other factors

When considering pregnancy other factors may need to be taken into account. Many of the drugs used in the treatment of MS are inadvisable during pregnancy and breastfeeding. Steroids may be used with relative safety in pregnancy[20]. However, many pregnant women choose not to have steroids, particularly as they have no bearing on the degree of recovery from the relapse.

There is limited data on the use of disease modifying therapies in pregnancy. Women are usually advised to cease treatment three months before attempting to become pregnant, and recommence once breast feeding has ended. Immunosuppressive and some symptom management drugs may cause physical defects in the developing embryo.

As more evidence emerges regarding the link between MS and vitamin D, it is prudent for women with MS to supplement with vitamin D during pregnancy, if they are not already doing so. Vitamin D supplementation during pregnancy may lower the MS risk for the foetus, as well as provide other health benefits, and is now recommended (at a low dose) for all women[21]. However, as yet there is no clear guidance on appropriate dosage for pregnant women with MS.

Another consideration is the level of disability of the mother and the availability of help with the care of the baby, should this be necessary. Women with MS should be encouraged to plan for the postnatal period, in the event of relapse, utilising practical help from family and friends, or statutory assistance eg from social services, or via the health visitor. Local

MS mother and baby groups can be invaluable in providing peer support and preventing feelings of isolation. Levels of fatigue should also be taken into account, bearing in mind that this common symptom can be exacerbated by the pregnancy itself and by subsequent disturbed nights.

MS is unpredictable and therefore decisions about having children can be difficult to make. The health professional can achieve a great deal by encouraging exploration of all the issues, many of which will be uncomfortable, and providing up to date information and support.

Menopause

Menopause does not appear to have any effect on MS either positive or negative, although there has been little research in this area[22]. However, there is anecdotal evidence, as well as a few small studies, indicating that symptoms which worsen during menopause may be responsive to hormone replacement therapy (HRT). The majority of women with MS who have used HRT report improvement rather than deterioration in their condition, but any potential benefit must be evaluated against possible risks. Since loss of bone density and osteoporosis may be a problem for people with MS[23], the beneficial effect of HRT on reducing the risk of osteoporosis should be taken into account.

Health screening

It is important that women with MS should be offered all relevant health screening, for example for cervical and breast cancer[24]. Unfortunately access to screening tests can be restricted for women with chronic disabling conditions, due to substantial physical barriers (eg mobile breast screening units with steps) thus limiting health promoting activities critical to a healthy life[25].

References

1. Orton SM, Herrera BM, Yee IM, et al. Sex ratio of multiple sclerosis in Canada: a longitudinal study. Lancet Neurol 2006;5(11):932-6.
2. Smith R, Studd JW. A pilot study of the effect upon multiple sclerosis of the menopause, hormone replacement therapy and the menstrual cycle. J R Soc Med 1992;85(10):612-3.
3. Zorgdrager A, De Keyser J. Menstrually related worsening symptoms in multiple sclerosis. J Neurol Sci 1997;149(1):95-7.
4. Houtchens MK, Gregori N, Rose JW. Understanding fluctuations of multiple sclerosis across the menstrual cycle. Int J MS Care 2000;2(4):7-14.
5. Wilson S. Premenstrual worsening of MS symptoms. Way Ahead 2001;5(3):14.
6. Holmqvist P, Hammar M, Landtblom AM, et al. Symptoms of multiple sclerosis in women in relation to cyclical hormone changes. Eur J Contracept Reprod Health Care 2009;14(5):365-70.
7. Confavreux C, Hutchinson M, Hours MM, et al. Rate of pregnancy-related relapse in multiple sclerosis. N Engl J Med 1998;339(5):285-91.
8. Devonshire V, Duquette P, Sadovnick AD. The immune system and hormones: review and relevance to pregnancy and contraception in women with MS. Int MS J 2003;10(2):44-50.
9. Birk K, Giesser B, Werner MA. Fertility, pregnancy, childbirth and gynecologic care. In: Kalb RC, editor. Multiple sclerosis: the questions you have - the answers you need. 3rd ed. New York: Demos Medical Publishing; 2004. p329-46.
10. Andersson K, Odlind V, Rybo G. Levonorgestrel-releasing and copper-releasing (Nova T) IUDs during five years use: a randomized comparative trial. Contraception 1994:49(1):56-72.
11. Smeltzer SC. The concerns of pregnant women with multiple sclerosis. Qual Health Res 1994;4(4):480-502.
12. Tillman AJ. The effect of pregnancy on multiple sclerosis and its management. Res Publ Assoc Res Nerv Ment Dis 1950;28:548-82.
13. Confavreux C, Vukusic S, Adaleine P, et al. Pregnancy and multiple sclerosis (the PRIMS study): two-year results. Neurology 2001;56(Suppl 3):A197.
14. Langer-Gould A, Huang SM, Gupta R, et al. Exclusive breastfeeding and the risk of postpartum relapses in women with multiple sclerosis. Arch Neurol 2009;66(8):958-63.
15. Portaccio E, Ghezzi A, Hakiki B, et al. Breastfeeding is not related to postpartum relapses in multiple sclerosis. Neurology 2011;77(2):145-50.
16. Vukusic S, Hutchinson M, Hours M, et al. Pregnancy and multiple sclerosis (the PRIMS study): clinical predictors of postpartum relapse. Brain 2004;127(6):1353-60.
17. Jalkanen A, Alanen A, Airas L. Pregnancy outcome in women with multiple sclerosis: results from a prospective nationwide study in Finland. Mult Scler 2010;16(8):950-5.
18. van der Kop ML, Pearce MS, Dahlgren L, et al. Neonatal and delivery outcomes in women with multiple sclerosis. Ann Neurol 2011;70(1):41-50.
19. Compston A. The genetic epidemiology of multiple sclerosis. Philos Trans R Soc Lond B Biol Sci 1999;354(1390):1623-34.
20. Ferrero S, Pretta S, Ragni N. Multiple sclerosis: management issues during pregnancy. Eur J Obstet Gynecol Reprod Biol 2004;115(1):3-9.
21. National Institute for Health and Clinical Excellence. Antenatal care: routine care for the healthy pregnant woman. NICE Clinical Guideline 62. London: NICE; 2008.
22. Coyle PK, Halper J. Meeting the challenge of progressive multiple sclerosis. New York; Demos Medical Publishing: 2001. p93.
23. Hearn AP, Silber E. Osteoporosis in multiple sclerosis. Mult Scler 2010;16(9):1031-43.
24. Stuifbergen A, Becker H. Health promotion practices in women with multiple sclerosis: increasing quality and years of healthy life. Phys Med Rehabil Clin N Am 2001;12(1):9-22.
25. Smeltzer SC. Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities. Fam Community Health 2006;29(1 Suppl):35S-43S.

MS Trust resources

Pregnancy and parenthood factsheet

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.

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