Chapter 18

Women with M.E.

Women seem to be affected by M.E. about three times as often as men in the age group 20-50, the years of both employment and fertility. Of course, in institutions where outbreaks occur, e.g. an army camp, or a nurses' residential home, there may be 100 per cent of the men or women affected. Yet, because of what seems to be M.E.'s 'bias' towards women, some doctors wrongly conclude that hysteria and neurosis contribute to the disease. This is inaccurate, speculative and scientifically unproven rubbish, and is insulting to women. This attitude continues to prevail, however, mainly among paternalistic older male doctors.

In fact, the reasons for the female/male ratio in M.E. are simple, if one accepts that the illness is virus triggered, often in people who are stressed or exhausted: Who are the people most exposed to viruses, particularly enteroviruses? Who are the people most likely to have to carry on working even when they are ill with a virus infection, or to have to return to work before properly recovered? The high-risk occupations for contact with enteroviruses are:

1. Teachers, especially of primary school.
2. Mothers, many of whom hold two jobs - homemaker plus outside paid work.
3. Nurses and those in other health care jobs.
4. Agricultural and sewage workers (yes, these are usually men).
5. To some extent, all jobs with high levels of public contact expose the worker to more viruses.

Of these, the people least likely to be able to rest enough from a viral infection are mothers of young children, teachers, and all health care workers, particularly nurses. A man with an office job, not coming into contact with a lot of children, who can sign off work for a week and be cared for at home if he gets flu, is probably at lower risk of M.E. This is not sexist propaganda, just commonsense observation!

There may also be a hormonal link with the conditions in the body that are right for M.E. to develop, but the mechanisms of this are not established. It may just be coincidence that the child-bearing years (18-40) are also the years of maximum hard work in high-risk jobs.

Problems Particular to Women with M.E.

- Menstrual periods - painful, irregular, heavy, or disappearing altogether.
- Endometriosis
- Premenstrual syndrome (often called PMT), which may become worse with M.E.
- Pregnancy - to be or not? Will the baby be affected? Contraception - is the pill OK?
- Menopause plus M.E. - may make each other worse
- Cystitis
- Vaginal infections
- Relationships and sex

Not every woman who gets M.E. will have problems in any of these areas. And of course a lot of women who do not have M.E. suffer from these gynaecological problems, but they may be much worse after developing this illness.

Periods

In some women, their cycle may become longer, shorter or irregular. Periods may be lighter or heavier than before, or even disappear during severe illness. These changes may happen with any long-term illness, also with chronic stress.

If periods become heavier, then extra iron and vitamin C are indicated. There is sometimes a disturbance of thyroid function with M.E., and this may be associated with prolonged flow.

Tampons are better *not* used during a period, because of the increased risk of vaginal infection.

Endometriosis

There are a significant number of women who suffer from an unpleasant gynaecological condition called endometriosis, as well as having M.E. In endometriosis, tiny pieces of endometrium (the lining of the womb, which is shed with every period), grow outside the womb. These abnormally situated endometrial tissues can be found anywhere, mostly lying on the outer surface of the womb, on the bladder, on the large bowel, or the ovaries and their supporting tissues. These 'seeded' tissues grow and then bleed at each period, and cause a lot of pain, and also scar tissue.

Typical symptoms are:

- Severe period pain
- Deep pelvic pain during and after intercourse
- Unexplained lower abdominal and pelvic pain, any time in the cycle
- Infertility
- Irregular bleeding or bleeding from other sites, such as the bladder or rectum

The condition can only be diagnosed with certainty by surgery or laparoscopy. The cause of endometriosis is not understood. It can affect women at any age from puberty up till the onset of the menopause. There appears to be an association with Candidiasis, and current research is finding abnormal immune functions similar to those in M.E. It is possible that a common mechanism predisposes a woman to having both endometriosis and M.E.

Current treatment for endometriosis is either hormonal - something to suppress oestrogen levels or surgical. The latter involves removing affected tissues, often including the ovary and Fallopian tube, or a hysterectomy. For a lot of women with this condition, a big problem is getting their doctor to recognise it; he or she may instead

dismiss their increasingly severe menstrual and pelvic pain as psychological, and refuse to refer for a specialist opinion.

Endometriosis sufferers with M.E. need to be cautious about hormone therapy, which might cause a severe M.E. relapse in some cases. High dose essential fatty acids such as evening primrose oil, B vitamins, magnesium, and anti-Candida treatment may be worth trying before agreeing to more drastic treatment.

I have described endometriosis in some detail, because of the increasing evidence that the condition may be more common in M.E. than in non-M.E. women, and because anti-Candida approaches may help (see Chapter 13). Some women with M.E. may attribute all pelvic symptoms to the M.E., and not seek help and further diagnosis - another reminder that when you have M.E., you must not assume all new symptoms are caused by it - especially pain, which may be due to something else and may be treatable.

Premenstrual Syndrome

Also commonly known as PMT - premenstrual tension, though tension is not the only symptom, but only the one most obvious to other people! /Premenstrual syndrome means that symptoms appear only during the 10 days before a period and are relieved when the period starts. Common symptoms are:

- weight gain
- bloating
- tender, swollen breasts
- irritability
- irrational behaviour
- depression
- weeping
- mood swings
- insomnia
- food cravings (usually for sugar and chocolate)
- headaches.

Many of these symptoms are due to fluid retention, and overlap with Candidiasis (which may contribute to PMS). If the condition has been experienced before M.E., then it may become worse once you have M.E. as well.

Measures to Improve PMS
Avoid blood-sugar swings by having small, frequent meals of complex carbohydrates regularly, and forgoing sugar and red meats. Stimulants such as coffee and tea should be reduced. Salt intake should be cut down.

The following supplements are of proven value:

- Gamma linoleic acid as evening primrose oil (EPO): at least 2 gm daily. If EPO is being taken to help M.E. it is a good idea to increase the dose during the premenstrual time.

- Magnesium: 250-500 mg a day
- Vitamin B_6: 50mg a day in addition to B vitamins taken as part of a good multivitamin preparation.
- The homoeopathic remedy Sepia is useful for symptoms of exhaustion, weariness, and depression.

It is also important to be aware of any reduced mental function or emotional control at this time, and to avoid tasks involving important decisions, and situations you know from experience will bring out your worst side. (I try to avoid driving if PMT is bad, for fear of hitting other cars in rage or impatience!)

If the PMS is severe and the subject is over 40, it may be worth asking for hormone assessment from a doctor. I know two women who suffer from M.E. plus severe PMS depression, who have been helped by hormone therapy (commonly a small dose of progesterone). It may seem strange that 1 mention this, in apparent contradiction to my advice against taking the contraceptive pill in Chapter 16, and below. However, no treatment is 'black and white' with M.E. It is important to remember that other treatable medical conditions, in this case menopausal premenstrual depression (which can be devastating in M.E.), may need to be diagnosed and treated with conventional treatment.

Most of the symptoms of PMS are probably due to water-retention. This mechanism also happens in M.E., apart from PMS, and contributes to weight gain, headaches and other brain symptoms.

Pregnancy

No doubt quite a number of women who have M.E. have successful pregnancies. Advice is commonly given from patient support groups that M.E. will not harm the baby. No one denies that there will be extra fatigue during the early years of caring for babies and young children. However, the most serious questions in the minds of women who have diagnosed M.E. and wish to have a baby, are these:

What chance is there that my illness could harm the baby? Can M.E. be passed on to a young child? Will my husband and 1 be able to cope with the extra demands of pregnancy, labour, and sleep loss after the birth?

There are no simple answers to these questions. Early research has found a small but definite number of M.E. pregnancies that have not progressed normally.

Any virus, if active during early pregnancy, may occasionally cause miscarriage, or abnormalities in the newborn. Rubella (German measles virus) and cytomegalovirus are well-known culprits. In a 35-year follow-up of family contacts of proven cases of enterovirus infection (in one area of England), Dr John Richardson, general practitioner, estimated a foetal loss of 30 per cent (of which at least 5 per cent is natural loss). This includes miscarriage, stillbirth and congenital abnormalities. (Personal communication from Dr B. Dowsett.)

There is also the probability that there is some inherited factor which may make the child more susceptible to M.E. - in the same way that a tendency to allergies is inherited (and seems to be more common among relatives of M.E. sufferers). In this way a mother may pass on a gene that makes the child vulnerable to getting M.E. Further research may clarify this potential hazard of childbearing. Any inherited susceptibility to M.E. applies, of course, to fathers as well as mothers.

Some M.E. women feel better throughout pregnancy (which is a natural immune suppressant) but relapse after an exhausting birth, or with the post-natal drop in hormones. Some are ill throughout pregnancy. The consensus of advice from doctors, and from mothers who have experience of M.E., is to put off pregnancy until the M.E. has stabilised and signs suggesting infection (e.g. fevers, diarrhoea, lymph glands, throat infections) are settled.

Then, only consider it if the mum-to-be can rest well during pregnancy, and if plenty of domestic help is planned (and budgeted for - more important than fancy frills for the baby) after the birth. I have not heard of any evidence to show that breast-feeding passes on M.E. to an infant. Breast-milk, if available, will provide the best protection against other infection, and also the best source of natural GLA (an essential fatty acid) to protect the infant against developing allergies. Obviously good nutrition is supremely important during pregnancy and while breast-feeding. A useful source of information on nutrition for pregnancy, especially for women with allergies, chronic infections or a history of pregnancy disasters of any kind, is the organisation Foresight.

Even the strongest of new mothers can suffer from post-natal depression, lack of sleep, and exhaustion. M.E. will not exempt you from these tribulations! However, the joy of a new child may well outweigh the problems, and a decision about embarking on a pregnancy must be yours and your partner's.

Childbirth

The question of drugs during labour, such as painkillers, gas and air, or an epidural, is one to discuss beforehand with your obstetrician and midwife. Many women with M.E. do cope quite well with labour, however exhaustion in the second stage may set in earlier than normal, so that there may be a greater likelihood of needing help (e.g. forceps) with delivery. It is wise to let the health workers concerned with your pregnancy and delivery know in advance about M.E. and how it affects you, emphasising the nature of the muscle fatigability.

Contraception

This is obviously important if pregnancy is thought to be a potential hazard, and should be discussed with your GP or a family planning clinic. The pill has many drawbacks even for non-M.E. women:

- Increases the likelihood of candida infections
- Reduces the available levels of vitamin B_6
- Increases the likelihood of depression
- Interferes with carbohydrate metabolism.
- Zinc deficiency is associated with taking the pill.
- The pill has been shown to affect the function of the immune system.
- Women who have taken the pill for some years have increased incidence of allergies and immune dysfunction diseases.

It is probably safer to avoid the contraceptive pill if you have M.E., for all the above reasons, and also because female hormones are related to steroids and might in theory have adverse effects on the body's own steroid production and interfere with natural immunity.

Intrauterine devices - 'coils' - can lead to infection in the womb and heavy periods, complications anyone with M.E. would wish to avoid. The safest birth control would be to use the barrier methods: A diaphragm or cervical cap plus spermicidal cream. Or a combination of a condom plus spermicidal cream.

The alternative, if you and your partner are sure you do not want any children in the future, is sterilisation tuballigation in the woman or vasectomy for the man. These methods are virtually 100 per cent effective for birth control, but are final, and couples need careful counselling before making this decision.

Menopause

There is nothing you can do stop the passage of time if you are over 40. The change of life is a fact of life. In many women this time is passed uneventfully, but others experience distressing symptoms, which may be confused with chronic fatigue syndrome by those without clear knowledge of CFS or M.E. These are:

- abnormal fatigue
- mood swings
- depression
- sweatings
- flushings.

Anyone familiar with the true features of M.E. will be able to distinguish M.E. from the menopause, as the former has the particular muscle fatigability, and symptoms made worse by exercise - not the same as the general weariness and slowing down of a woman during the menopause. The problem the menopause poses with M.E. is that one seems to make the other worse. Also, menopausal women with severe symptoms, especially of fatigue, may wrongly fear that they have M.E. This makes diagnosis and exclusion of other conditions especially important for the self-diagnosed sufferer at this age. If M.E. is already diagnosed and pre-exists, the onset of the menopause may exacerbate some symptoms. Any major life change is a stress on the body, including puberty and the

menopause. If M.E. depression is much worse at this time, consider asking your doctor if hormone therapy might help (see above in section on PMS).

Cystitis

This bladder problem is not confined to women, but seems to be more common among them. Symptoms of frequency of, urgency of, or burning on passing water, blood in urine (if severe), lower abdominal pain, and fever, suggest infection in the bladder.

Management

Drink masses of water, rest completely, and see your doctor as soon as possible so that a urine specimen can be collected in a special bottle for bacteriological testing. A simple remedy, obtainable from any pharmacy, is potassium citrate (Mist Pot Cit), which makes urine more alkaline and reduces the burning.

If the symptoms are not severe, it is better to wait until results of the urine culture before starting antibiotics. Then, if no bacterial infection is found, you will not have unnecessary antibiotics (a bad thing with M.E.), and if infection is present, the drug sensitivities will be found and the correct antibiotic prescribed.

What happens sometimes is that all the nasty symptoms of a bladder infection are present, but no bugs are found in the urine. It is possible in such cases that:

- the infection is a yeast one (Candida)
- food allergies are another possible culprit
- there is some disturbance of bladder sensation and bladder function, locally or maybe centrally in the brain.

Anyone who has repeated attacks of cystitis should make sure her nutrition is good and take extra supplements to boost resistance to infection.

Some herbs are helpful for bladder symptoms, e.g. Potter's ‘Antitis tablets' and Marshmallow root.

The homoeopathic remedy for acute symptoms is usually Cantharis.

However, if you have an acute attack of cystitis, you must see a doctor and have any bacterial infection identified and treated. Untreated bacterial bladder infections can spread to the kidneys and cause serious problems - with or without M.E.

Vaginal Infections

Recurrent thrush is a common female problem made worse with M.E. However, any abnormal discharge should be investigated if it persists. It may indicate some other infection which needs treatment. Thrush, caused by the yeast Candida Albicans, typically causes a white discharge, with intense itching around the vaginal entrance. If the discharge is yellow, offensive or bloodstained, you must see your doctor. Thrush tends to flare up in conditions of poor health, stress, too much sugar in the diet, diabetes, taking birth control pills, local conditions of heat and humidity (e.g. wearing nylon tights and pants, or in hot humid weather) and poor hygiene.

General anti-Candida measures will help (see Chapter 13), plus treatment with vaginal pessaries and cream.

The latter alone will not clear up thrush for long if your diet is wrong. As the bugs causing vaginal infections are transmitted to and from a sexual partner, it is better to abstain from sex while the infection lasts, and it is best for your partner to get treated as well. Another common bug is Trichomonas, which like Candida is widespread and easily transferred between partners.

The use of tampons during a period may increase the likelihood of vaginal infection, as they act as a reservoir of blood in which bugs multiply, especially if not changed regularly. There are recorded cases where a forgotten tampon has led to a very severe infection which has spread to the bloodstream. While the majority of non-M.E women can happily use tampons all their lives with no complications, I believe that if you have M.E. it is prudent to minimise risks of any infection in the body.

Sexual Relationships

The problems sexual relationships (or rather the lack of them!) cause with M.E. are discussed more fully in Chapter 21. Loss of interest in sex is a very common symptom for both men and women with M.E. and any chronic fatigue syndrome. The body wishes to use available energy for what it considers more important activities. Loss of interest in sex is also a common symptom in severe depression, low thyroid function, and many other chronic illnesses. If depression is a prominent complication of M.E., treatment of this by antidepressants or counselling might improve an M.E. person's sex life somewhat.

Even if always exhausted, a wise woman will try and find times when sex is least stressful, to reassure a caring partner that he is still loved and needed. As with post-menopausal women, vaginal dryness and discomfort may be discouraging, but using KY lubricating jelly may sometimes help.

Loss of an adequate sex life (every couple has different needs) can be very detrimental to a relationship already rocked by the effects of illness on one and perhaps both partners. Sometimes there are psychological blocks as well as physical constraints, and some time with a skilled counsellor may help one or both partners.