



## Pregnancy in Women with Chronic Fatigue Syndrome (ME/CFS)

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Chronic Fatigue Syndrome is a serious, complex and disabling illness, which affects at least a million American men, women and children of all races and economic backgrounds. The illness occurs worldwide and is also known as Myalgic Encephalomyelitis (ME) and as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). Currently the acronym ME/CFS is increasingly being used.

The debilitating fatigue of ME/CFS is accompanied by a wide array of immune, neurological, endocrine, cardiovascular and other symptoms. All the ME/CFS symptoms are made worse by physical and mental activity, are not relieved by rest and result in a substantial loss of occupational, personal, social and educational activities.

### **Deciding to Have a Child for Women with ME/CFS**

Four times as many women as men suffer from the illness and it usually affects women during their peak childbearing years. As a result, many women who are debilitated by ME/CFS have to make the difficult decision about whether or not they should have a child. Younger women may be able to wait and hope for improvement before getting pregnant, but waning fertility is a concern for older women. Countless women with ME/CFS have had successful pregnancies and healthy children. However, many of them found that raising their children was extremely difficult. Both parents should be in agreement, because the child's father will, of necessity, have to do much more for both mother and child than in families where the mother is healthy.

### **The Effect of Pregnancy on ME/CFS**

ME/CFS symptoms tend to improve in about one third of pregnant ME/CFS patients, are unchanged in about one third and worsen in about one third of them. Many mothers feel worse during their second and later pregnancies. Mothers with ME/CFS need extra rest during pregnancy and some may need bed rest most of the time. Improvement during pregnancy usually occurs after the first trimester and is thought to be due to the effect of pregnancy hormones.

Within weeks of delivery, at least half the mothers either relapse or feel worse than before the

pregnancy. Symptoms are similar both before and after the pregnancy in about a third of mothers and symptoms are decreased in a minority.<sup>1</sup> Relapse after delivery is likely to be due to the extra effort needed to take care of a young baby, coupled with the loss of the elevated pregnancy hormones.

Many ME/CFS patients use both over-the-counter and prescribed medications to relieve symptoms. Some vitamins, such as folic acid, are beneficial both before and during pregnancy. In healthy women, folic acid has been shown to reduce the occurrence of neural tube defects in the child. However some medications can damage the fetus, especially in early pregnancy. The effects of most herbal preparations are unknown. ME/CFS patients should discuss all their non-prescription and prescribed medications with their doctors, and stop any which are potentially dangerous before pregnancy begins. Symptoms may worsen as a result of stopping the medications.

### **The Effect of Maternal ME/CFS on the Child**

There is a theoretical possibility that a virus, which might cause ME/CFS, could be passed to the fetus during pregnancy or delivery, or to the child during breast-feeding and affect the child later in life. There is no scientific evidence for any of these scenarios. Most women with ME/CFS have normal healthy children, but ME/CFS can occur in both mother and child. A recent survey found that 5% of the children of mothers with ME/CFS also developed the illness. Half of the affected children developed the disease as adults, and 42% of the children recovered.<sup>2</sup> Both genetic susceptibility and an infectious agent have been proposed as possible contributors to the risk of ME/CFS in these children.<sup>2</sup> ME/CFS is thought to be very uncommon in infants and in children under the age of five.

No difference in the risk of major or minor birth defects was found in children who were born after, compared with before, their mothers developed ME/CFS.<sup>1</sup> However, developmental delays and learning disabilities occurred in more than twice as many children who were born after compared with before their mothers developed the illness.<sup>1</sup> Some parents have opted for adoption, because of possible risks to their child.

### **The Effect of ME/CFS on Pregnancy**

Pregnancy is not recommended in the early stages of ME/CFS, when a woman is very ill and the diagnosis may be uncertain.

Many ME/CFS patients have problems, which reduce fertility, such as irregular periods, Endometriosis, or lack of libido. Infertility may be higher than the rate of 10% to 20% found in healthy couples.

First trimester miscarriage occurs in 10% to 20% of pregnancies. The miscarriage rate was higher, around 30%, in two groups of women with ME/CFS.<sup>1</sup>

A common symptom of early pregnancy is morning sickness, which is usually limited to the first trimester. In women with ME/CFS, this symptom may be more severe, lasting throughout the day and even persisting into the later months of pregnancy. The severe form of morning sickness, hyperemesis gravidarum, appears to be commoner in pregnant ME/CFS patients than in healthy women. Bed rest usually helps morning sickness. Complementary therapies such as fresh ginger or Sea-bands™ worn around the wrists may be useful. Prescribed medications are sometimes necessary.

Other pregnancy complications including vaginal bleeding, gestational diabetes, hypertension, pre-eclampsia, premature rupture of membranes, premature labor and low birth weight of the baby were found to be no more frequent in the pregnancies of ME/CFS patients, whether the pregnancy occurred after or before the patient developed ME/CFS.<sup>1</sup>

Prenatal care should start early in pregnancy. An early ultrasound scan will confirm the fetal age, the date of delivery and reassure the parents of the presence of a fetal heartbeat.

### **The Effect of ME/CFS on Labor and Delivery**

Mothers with ME/CFS will tire more quickly in labor than healthy mothers. If she also has Fibromyalgia, which is a common co-illness with ME/CFS, labor pain may be felt as being more intense than normal. It is important that mothers with ME/CFS should be given adequate pain relief and kept well hydrated in labor. An epidural anesthetic can be useful. Prolonged labor can be avoided and the baby delivered before exhaustion occurs by using a C-Section in the first stage of labor, or using forceps or a vacuum extractor in the second stage. A C-Section before labor may be recommended. C-Sections require an epidural or a general anesthetic. ME/CFS patients often require a much smaller dose than normal, of drugs given for pain relief in labor and drugs used for epidural and general anesthetics.

### **The Effect of ME/CFS after Delivery**

Many women with ME/CFS are exhausted by childbirth and need to stay in the hospital longer than normal. This is especially true for women delivered by C-Section. Arrangements for this possibility should be made before delivery.

Postpartum depression is two to three times more frequent in ME/CFS patients than in healthy mothers. Treatment with supplemental hormones may be as effective as antidepressants.<sup>3</sup>

Previously healthy mothers can occasionally develop ME/CFS after delivery. Their ME/CFS could have been triggered by the effect of changing hormone levels on the immune system.

### **ME/CFS and Breast Feeding**

Many mothers with ME/CFS successfully breastfeed their babies and it is a lot less trouble than preparing formula. Some mothers even feel better while they are breastfeeding. Other mothers find nursing their babies is exhausting and for them, someone else can help with bottle-feeding. Mothers should weigh the well-known benefits of breastfeeding against unproven risks of exposing their infant to a possible ME/CFS infectious agent in breast milk.

Many women feel better during pregnancy, but they relapse after delivery. If so, previously helpful ME/CFS medications may be beneficial. If these are medications that pass into the breast milk and could adversely affect the child, then bottle-feeding is recommended.

### **Coping with Child Rearing**

Having a child is very rewarding, but taking care of an infant - and later on a toddler - is hard work. When the mother has ME/CFS, childcare can be very exhausting. Both parents will suffer problems that other families do not face. Having a good support network is essential. Advice on how to cope can be obtained from other mothers in a local support group. Having ME/CFS can discourage some women from having children. A recent survey found that 21% of a group of ME/CFS patients decided not to have a child because they thought that their debility would interfere with their ability to raise their child.<sup>1</sup>

### **For more Information on ME/CFS**

Website: [www.njcfsa.org](http://www.njcfsa.org)

Info line: 888-835-3677

### **References**

1. Schacterle S, et al. *Arch Intern Med.* 2004;164:401-404.
2. Underhill R, et al. *J CFS* 2006;13(1): 3-13
3. Studd J, et al. *Lancet* 1996; 348:1384.