Deciding whether or not to have children is a life-changing decision for any couple, fraught with many questions and concerns. For women with fibromyalgia (FM), chronic fatigue syndrome (CFS), or a related illness, this decision is even more complex. Since these illnesses are most commonly seen in women of childbearing age, the choice of whether or not to have a child is one that many FM/CFS sufferers will have to make.

Many women with FM/CFS struggle with a number of questions, such as: Can I conceive and give birth to a healthy baby? How will I feel during pregnancy and after childbirth? Will I be able to care for a child? The answers to these questions are complicated by the paucity of research in this area. The studies that do exist are small, and often conflicting. Most of the information available is based on clinical and anecdotal evidence, rather than scientific data.

In 2004, the National Fibromyalgia Partnership conducted an online poll which helped to illuminate the impact of FM/CFS and related illnesses on the decision whether or not to have children. [Please note that this poll was not scientific and was used for general, informational purposes only; no controls were in place to monitor how votes were cast.] Over 200 women responded. Of these, 44% had been diagnosed with FM, 13% with CFS, 38% with both FM and CFS, and 5% with another illness.

Fifty-nine percent of poll participants reported that fibromyalgia (or a related illness) "very much" or "somewhat" affected their decision whether or not to have children, while 6% said "only a little." Only 28% stated that illness was not a consideration. Some who elected not to have children cited fears of making the illness worse and not being able to care for a child. One respondent commented, "Knowing I could not take anything for pain made the prospect of a nine-month pregnancy unbearable." In fact, 21% of respondents decided not to have children due to their illness, while
46% reported, "My illness was a concern, but I decided to still have children." The remaining 32% fell into the "Other" category, which included women who already had a child and decided not to have more children, those who were unable to conceive or complete a pregnancy, those whose illness was triggered during pregnancy or childbirth, and those who were still in the process of making a decision.

These results suggest that the majority of FM/CFS sufferers weigh this life-altering decision carefully, and that – not surprisingly – their illness plays no small role in their ultimate choices.

Pregnancy's Effect On Symptoms

Like most things related to FM/CFS, the experiences of pregnancy and childbirth are often as varied as the illness itself. Despite the lack of comprehensive research, FM/CFS experts and mothers alike have weighed in on the whole range of issues related to having children – from fertility and pregnancy to labor/delivery and recovery after childbirth.

Most of the published information that does exist is based on the experiences of CFS patients (many of whom are also diagnosed with FM), rather than patients whose sole diagnosis is fibromyalgia. The only published study specifically on fibromyalgia and pregnancy was published in the *Scandinavian Journal of Rheumatology* by Wigers et al., in 1997. The study followed 26 women with FM and a total of 40 pregnancies. With the exception of one patient, all the women reported a worsening in FM symptoms during pregnancy with the last trimester experienced as the worst period.

However, these findings are somewhat contrary to the clinical observations of many physicians who see great numbers of FM/CFS patients. Charles Lapp, M.D., a CFS expert and founder of the Hunter-Hopkins Center in Raleigh, NC, has written about his own clinical observations of CFS patients who become pregnant.* He reviewed 27 medical charts of women in his practice who became pregnant while they had CFS and found that 25 of them felt better during pregnancy. The reason for this may involve the immune system, which is suppressed during pregnancy in order to prevent the fetus from being rejected. A similar improvement in symptoms during pregnancy is seen in autoimmune conditions, such as multiple sclerosis. Hormonal changes may also play a role, as well as the increase in circulating blood volume that occurs during pregnancy.

Other FM/CFS clinicians concur with Dr. Lapp's findings. According to Charles Shepherd, M.D.,** a well-known CFS expert in the U.K., "the general view among doctors that have been involved in the care of women with CFS who have become pregnant is that around three-quarters notice that their symptoms improve, sometimes quite significantly." On the other hand, Dr. Lapp points out that one-third of the patients he followed experienced a worsening of symptoms after they gave birth, which Lapp characterized as "a bad relapse."

Many women with FM/CFS worry about the possibility of passing their illness to their unborn child. No definitive proof exists as to whether or not either FM or CFS can be transmitted to a child. While the issue of a "genetic link" in FM/CFS is often discussed (some research has found that the illness seems to run in some families), there are no reports of a child being born with FM or CFS. If these illnesses are caused by a virus, it is possible that the virus could be transmitted to the baby as it passes through the birth canal or through breast-feeding. While the likelihood of this is very low, some parents who are concerned about this consider Cesarean-section deliveries and/or bottle-feeding.


Our NFP poll results fell somewhere in the middle of the most positive and negative of existing research and clinical data. Of the 65 participants who had been pregnant while ill with FM/CFS, 39% reported that their pain level decreased, 31% noted an increase, while 20% said that their pain stayed about the same. As for fatigue, the results were less encouraging; only 12% described a decrease in fatigue, 52% reported an increase in fatigue, and 31% said their fatigue stayed about the same during pregnancy.

Fertility, Pregnancy, & Birth

A 1998 study in the American Journal of Medicine by Harlow et al., found an increased incidence of menstrual and reproductive problems in patients with CFS. The research, which studied women with and without CFS, revealed that the CFS patients were more likely to have suffered irregular cycles, periods of amenorrhea (lack of menstrual periods), sporadic bleeding between periods, and ovarian cysts. Such gynecological abnormalities could result in difficulty in getting pregnant or in completing a pregnancy. Other research has found an increased risk of miscarriage in patients with CFS. A recent study of CFS and pregnancy published in the Archives of Internal Medicine by Schacterle and Komaroff found a 22% higher rate of miscarriage in pregnancies that occurred following the onset of CFS. However, the study authors admit that maternal age could be a factor in these results.

The same study found that developmental delays or learning disabilities were reported 13% more often in the children of women who became pregnant after the onset of CFS; but again, the study authors admit that maternal age or other differences between the groups could be confounding variables. They point out that these findings should be investigated by larger studies using control populations. Dr. Lapp, in his chart review, did not find the rate of miscarriages higher than that in the general population. Says Lapp, "The majority of women with CFIDS seem to have normal, healthy children." Even the 1997 study in the Scandinavian Journal of Rheumatology found that FM had no adverse effect on the outcome of pregnancy or the health of the newborn.

Doctors universally recommend that most, if not all, medications used to treat FM/CFS should be discontinued before getting pregnant because they may be harmful to the developing fetus. This includes over-the-counter medications, herbal remedies, and supplements. In our online poll, 73% of respondents stopped their medications while they were pregnant, which may explain the worsening of symptoms for some people. To reduce the difficulty of discontinuing medications, women can talk to their doctors about how to taper off certain drugs and what alternative techniques they can use to address pain and other symptoms.

In addition, the extreme expenditure of energy during the process of labor and delivery can cause an exacerbation of symptoms after childbirth from which it can be difficult to recover. Dr. Shepherd points out that "this is the time when there is a real risk of worsening symptoms or a major relapse..." Therefore, it is essential for a pregnant woman with FM/CFS to discuss these issues with her doctor or midwife well in advance of the baby's due date. An epidural can help conserve a woman's energy during delivery and facilitate recovery afterwards.

Mothers-to-be with FM/CFS should also talk with their doctors about the advantages and disadvantages of breast-feeding versus bottle-feeding. While breast-feeding provides some important health benefits to the baby (and eliminates the time and energy needed for bottle preparation), it requires that the mother's medications continue to be restricted after pregnancy. Bottle-feeding also allows other people to help with the feeding, especially at night, making it possible for the mother to get more rest.

Weighing The Options

There are a variety of practical issues that must be weighed when contemplating whether or not to have a child. A major concern for most couples is money. Having a child can be an expensive proposition, and people with FM/CFS may experience added pressure if they are unable to work or need to hire extra help with childcare or household tasks.
It is also vital for the couple to have a strong relationship in order to cope with the challenges of illness and parenthood. Ideally the non-ill partner should be supportive and willing to pick up the slack when the person with FM/CFS is ill or exhausted. Having support from family and friends is also essential.

Dr. Shepherd recommends that patients with CFS evaluate their current state of health and how long they have been ill. He advises that those who are still in the very early stages of the illness wait until the symptoms have started to improve, or at least six months in any case. "I would not recommend going ahead if you are still experiencing a lot of flu-like symptoms such as sore throats and enlarged glands, temperature control problems, night sweats, etc."

However, the desire to wait for symptoms to improve must be weighed against fertility issues, since fertility declines as women age. In a 2002 survey of 72 women who became pregnant and gave birth while ill with FM/CFS, conducted by Caroline Walker, 30 percent of first pregnancies occurred in women who "waited to improve but eventually gave up waiting and went ahead anyway."

**Bringing Up Baby**

Parenting requires a considerable amount of physical and emotional energy and can be an immense challenge, even for a healthy person. Yvette Keitley, a mother with CFS who wrote an article on this topic for a British website called ME/CFS Parents, writes, "I knew I wanted a baby regardless of my illness – it was more the unanswered questions surrounding our decision. As a friend said when I told her I was expecting, 'How on earth will you cope?'"

According to Dr. Lapp, coping with childcare is the largest factor in deciding whether or not to have a baby. In the 1997 study in the Scandinavian Journal of Rheumatology, 77% of the women with FM admitted that they required help to care for the baby, compared to 43% of the group without FM. The first few months are particularly demanding, and this can be especially difficult, since many women experience a worsening of FM/CFS symptoms in the first 6-12 months after giving birth.

In fact, suffering a severe relapse or flare-up due to pregnancy or childbirth is a fear shared by many people with FM/CFS who are contemplating having a child. Planning for a worst-case scenario in which one is unable to care for the baby is a wise idea. Friends and family, a nanny, or other childcare might all be ways to get needed help.

**An Emotional Decision**

Coping with FM/CFS can be emotionally difficult for anyone – feelings of loss and frustration with the limitations imposed by illness are common. These feelings are often heightened for mothers with FM/CFS. In Walker's survey, many women described feeling "alone, unsupported and guilty or depressed about being unable to do the 'normal' things a mother does with a child, ranging from basic care to going to baby and toddler groups and playing games." Nevertheless, most women with FM/CFS describe having a child as a very positive experience, despite their aggravated symptoms. The joy of being a parent and the sense of purpose it brings is uniquely satisfying, especially for those who may be unable to have a career because of FM/CFS.

Shannon, whose daughter Bethany is six months old, writes, "Some days I really do feel awful, especially if Bethany has been awake all night, but I know that even though I feel rough, there is one little person who loves me regardless. It makes me feel needed, a feeling I lost through being ill."

Couples who choose not to have a child because of FM/CFS face the same challenges as any couple who conclude that not having children is the right decision for them. These couples may have to cope with pressure from loved ones and a society that often regards women without children as an aberration, despite the fact that the number of childless couples is on the rise. According to 2002 data from the National Census Bureau, 44% of U.S. women aged 15 to 44
don't have children, which is 10% more than in 1990. It is important to point out that these numbers include women who may later give birth. A more telling statistic may be the percentage of women aged 40 to 44 – those at the end of their childbearing years – who do not have children. That number has hovered around 18% since 1994, up from 10% in 1976.

Of course, these statistics do not differentiate those who are "childless by choice" from those who have not had children due to infertility or other circumstances. It seems that women who decide not to have a child due to FM/CFS lie somewhere in the middle. To those women for whom having a family was an important goal now thwarted – like so many others – by illness, the decision can be especially painful. One woman in her late thirties, who says her FM was the most significant factor in her decision not to have children, describes her mixed emotions: "I feel like I have been cheated out of what is supposed to be the most precious of all life's experiences, but I remind myself that having a child would not be fair to either a child or myself, since I don't believe that I would be as good of a mother as I would like to be because of fibromyalgia."

Moreover, like so many aspects of FM/CFS, the decision not to have children due to the illness is often difficult for others to understand, which may lead to feelings of guilt and isolation. "I find it hard to explain to people that my illness is the reason I'm not going to have children," says one FM/CFS sufferer. "If I physically couldn't have a child, due to infertility or something else, then perhaps people would be more understanding, rather than questioning my decision."

On the other hand, couples who opt not to have children will naturally have greater freedom and quality time with each other, pleasures that frequently are already limited by chronic illness; and many find alternative ways to make their lives full and meaningful. Enjoying nieces, nephews, and god-children can be a special joy. Says one woman with FM/CFS who opted not to have children, "there are plenty of other ways to bring love to the world, to nurture someone else, to teach, and to share. I try to find one every day."

Ultimately, the decision whether or not to have a child is a very personal choice, and no one can be told the "right" thing to do. Most importantly, a couple should talk openly to each other about their feelings and concerns, and they should discuss the medical issues with their general physician, gynecologist, and/or FM/CFS specialist. A therapist or caring friend might be helpful in exploring the many emotional issues that surround such an important decision. No matter what the outcome – and the stumbling blocks and doubts along the way – women should know that they are not alone.

**Other Resources**

Website group formed for women interested in talking about the various issues of pregnancy: https://groups.yahoo.com/neo/groups/fmscfsandpregnancy/info

Chapter 40--"New Moms (& Dads) with Fibromyalgia," by Mark Pellegrino, M.D.

*Never to Be a Mother: A Guide for All Women Who Didn't-Or Couldn't-Have Children* (book)
by Linda Hunt Anton