MS: The Diagnosis That Doesn't Mean Missing Out On Motherhood

By Neda Ebrahimi , Teratogen Information Specialist, Motherisk

As a counselor with Motherisk, the Canadian partner of MotherToBaby and a service of the Organization of Teratology Information Specialists (OTIS), I hear many stories from women about pregnancy. Some of those stories strike cords with me. Their urgency and desire to make the healthiest decisions possible for their future children is both understandable and admirable. In honor of National Multiple Sclerosis Awareness Month, I give you ***Nina's story.***

Nina's Story

"I'm 31 years old, and I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS), when I was only 22. My first relapse was scary. I was writing my finals, and 2 days before my last final, I lost sight completely in one eye, and my legs felt so week and wobbly that I couldn't stand even for a second. After going to the hospital and receiving several courses of steroids over 10 days, I started to improve but it took 2 months for my symptoms to fully resolve. And then, everything went back to normal, as if nothing had ever happened. I received my diagnosis several months after, and it felt like a death sentence. I had 2 more relapses before my doctor put me on disease modifying drug (DMD), and I started with Infterferon-B1a. Over the last 8 years, I only experienced 5 more relapses. The last relapse I had was only a few months ago; I lost sight in my left eye, and numbness that ran from my face to my toes on just the right side of my body. I have always been able to work full-time except when I'm experiencing a relapse, for which I've had to take a month off. I am a dentist, so not surprisingly I can't carry out my job when I'm experiencing numbness in my hand. I met John 5 years ago at the MS clinic I used to visit. He was a nurse there. We fell in love, and despite of my illness he proposed to me last year, and we talked about having a family, with two children, hopefully one boy and one girl, and living happily ever after. It didn't initially worry me that one day I may want children. John is crazy about kids, and I feel my maternal instincts kick in every time I hold a baby. Since we got married, my anxiety has been increasing proportionally to my yearning for having a child. I know my MS can't be cured, at least not now, I know it can get worst over time, and eventually I may need support to carry out even simple tasks. Or Maybe I won't, and I would be one of the few who never enter the progressive state. I don't know if I'll be able to care for a baby and meet his or her demands. What will happen after my pregnancy? I really don't want to experience another relapse after I deliver. How am I going to manage my illness, and what will happen if I need to came off my DMD when I'm pregnant or breastfeeding? There are so many questions, and I don't know who to turn to."

Nina is not alone in her thirst for answers. MS is an autoimmune neurological disease with very different presentation. No two MS patients are exactly the same and symptoms can vary from just the occasional mild tingling in the finger tips to more severe symptoms that render the patient unable to walk or stand for several weeks. With Relapsing Remitting MS accounting for 85% of all MS cases, most patients will undergo a remissive state after an attack, and will resume their daily life with little or no hindrance. Some patients will continue to have modest symptoms during the remissive state which they learn to adapt to and manage by different medications and or lifestyle changes. As there are no current cures for MS, many MS patients live for decades with this disease, and must find the means to maintain a high quality of life as the disease progresses, which can be challenging in the later stages of the disease.

MS impacts many more women than men with a 3:1 ratio in North America. As the disease onset occurs during the reproductive ages, many women with MS face the dilemma of pregnancy at some point during their lives. Young women, like Nina, with MS planning pregnancies, have many questions. Because the disease presentation and progression varies from person to person, there is no exact answer and treatment and management must be tailored to the specific person's need. However, I'd like to address some of the most common questions to help all of the "Ninas" out there:

1. "Would the disease adversely impact the pregnancy and my developing baby"?
Up until the late 1950s, women with MS were advised to terminate their pregnancies. With our advancement in the field, we know that this is almost never necessary. Many women with MS continue to have healthy babies, and

research shows that there is no increased risk for having a baby with a structural malformation or developmental delay and many deliver healthy babies with no major complications. Although there is a trend toward lighter weight babies, the birth weight percentile remains in the normal range for most. Another observation has been the higher rate of miscarriage in the MS population with mixed results from different studies. The reason for this is not well understood, but the majority of miscarriages are in early pregnancy. While miscarriage rates in the general population are around 10-15%, in women with MS the rates are closer to 20%-30%. With successful conception, the chance of delivering a healthy baby at term is high, and women with MS should be assured that their disease is unlikely to cause harm to the developing baby.

2. "Would my baby also have MS"?
There is a complex interplay between genetics and environment leading to MS. While the risk of getting MS in the general population is 0.3%, having a parent with MS will increase this risk by almost 15 times. So children of women with MS may have a 3% to 6% chance of developing MS later in life, but the environmental and lifestyle factors may play the ultimate role in disease manifestation. Hence despite the genetic contribution, the risk for your baby developing MS remains small and can potentially be modified.

3. "If I stop my DMD when planning, what are the risks of having a relapse while I try to conceive?"
Depending on how long it takes to conceive, the drug free period prior to pregnancy may be a risky period for experiencing a relapse. While some women conceive after just one cycle, many will conceive after several months of actively trying to become pregnant. It will take 1 to 3 months (depending on the drug) to fully clear the system, and during this time, some may experience disease activity. If prior to starting the DMD you had very active disease, there is a risk that you'll experience a relapse when you stop the medication, especially if it takes more than 3 months for you to conceive. The decision to continue DMDs is highly individualized and is determined on a case-by-case basis. You and your neurologist will determine the best mode of action.

4. Would having a pregnancy make my MS progress faster?
Pregnancy has not been shown to speed the disease process. In fact, pregnancy is a state of remission for many women with MS, and a time for optimal wellbeing. It is well established that relapse rates reduce by 70% by the third trimester of pregnancy compared to the year prior to pregnancy. However after delivery the relapse rate increases, with 60% of women experiencing a relapse in the first 3 to 6 months postpartum. While the risk is increased in the postpartum period, the course of MS tends to return to its baseline, and no worse than what it was in the year prior to pregnancy. Some studies have found a protective effect with pregnancy, with a delay in the long-term disease progression; however, more studies are needed to confirm this finding.

5. Would I be able to continue my DMD through the pregnancy?
Although many women with MS go through remission in the pregnancy, some will continue to experience disease activity especially in the first two trimesters. The decision to continue DMDs is dependent on several factors, including the type of medication, disease activity in the year prior to pregnancy, and the type of control achieved with the given DMD. The use of glatiramer, Interferon Beta 1a/1b, in pregnancy have not been associated with an increased risk for malformations and if you achieved great control with these drugs, and are at a high risk of relapsing, your physician may consider continuing your therapy through the pregnancy. The newer drugs, especially the oral DMDs, have not been well studied, therefore it is recommended that you discuss with your neurologist the best plan for the course of your pregnancy. There are ongoing research studies looking at the outcome of pregnancies following exposure to these medications. MotherToBaby and its affiliates are engaged in such studies. For study information or for the most up-to-date information about newer medications used to treat MS during pregnancy, call from anywhere in North America toll-FREE 866-626-6847.

6. What if I have a relapse during pregnancy?
While relapses during pregnancy are uncommon, they may happen, and can be quite severe for some women. Steroids are usually used to treat those relapses, although some success has been shown with IVIg therapy as well. A women that experiences a severe debilitating relapse during her pregnancy, may require the standard steroid therapy, while a women that experiences a mild flare-up may choose, in collaboration with her physician, to abstain from treatment. Systemic steroid use in the first trimester has been associated with a very small risk for cleft lip and palate, and use in the second half of pregnancy may increase the risk for having a smaller baby and for delivering prematurely (before 37 weeks gestation). However, it is recommended that you speak with your health care provider before you stop or change any medication. The benefits of taking a steroid and treating your condition should be weighed against these small possible risks. For more information, check out this fact sheet online: https://mothertobaby.org/fact-sheets/prednisoneprednisolone-pregnancy/ or call anywhere in North America toll-FREE 866-626-6847.

7. Should I breastfeed or start my DMD right after delivery?
The postpartum period is a period with a high risk of experiencing relapses. Data on whether breastfeeding has protective effect has conflicting results. Some studies suggest a protective effect, possibly due to the delay of menses returning, while others show no impact. Information on safety of DMDs in the breastfeeding period are scarce, however given the large molecule size of glatiramer acetate, and Interferons, it is unlikely any will transfer into milk. If they do, they are likely not to be absorbed from the baby's gastrointestinal tract. There is no information regarding other DMD usages during lactation. The benefits of breastfeeding baby are numerous, but, ultimately, your functionality and ability to care for your child take priority. The decision to breastfeed or not may depend on your ability to breastfeed, especially since the demands of a newborn and the hormonal changes in the postpartum period can be very taxing on your energy levels and if you experience chronic fatigue due to your condition. Thus, if a woman (while consulting her physician) decides to breastfeed she may do so. However, if she needs to restart her DMD, currently she may be advised to stop breastfeeding.

Bottomline: While having MS poses physical and emotional challenges, it does not jeopardize a woman's capacity to motherhood. With careful planning and close collaboration with your doctors and healthcare providers, and especially with some support from family and friends, you will be able to have successful pregnancies, healthy children, and out of control teenagers, just like any other woman. So if becoming a mother is something you have always wanted and looked forward to, having MS is more of a bump in the road rather than a life sentence, and with some maneuvering you can achieve your dreams. Happy parenthood!

Neda Ebrahimi is a research associate and counselor at the Canadian Motherisk program, a non-profit MotherToBaby/OTIS affiliate that aims to educate the public about medications and more during pregnancy and breastfeeding. The Motherisk program is also a center for teaching and clinical research in the area of exposures in pregnancy and breastfeeding. Neda is pursuing her PhD in the field of Multiple Sclerosis in Pregnancy. To learn more about her work and about her study, email her at neda.ebrahimi@sickkids.ca or call 416-813-7654 ext. 204928. You can also call the Motherisk Helpline at 1-877-439-2744 and ask to be referred to the MS study.

MotherToBaby and its affiliates are services of the international Organization of Teratology Information Specialists (OTIS), a suggested resource by many agencies including the Centers for Disease Control and Prevention (CDC). If you have questions about MS, medications or other exposures during pregnancy or breastfeeding, call toll-FREE 866-626-6847 or visit MotherToBaby.org.