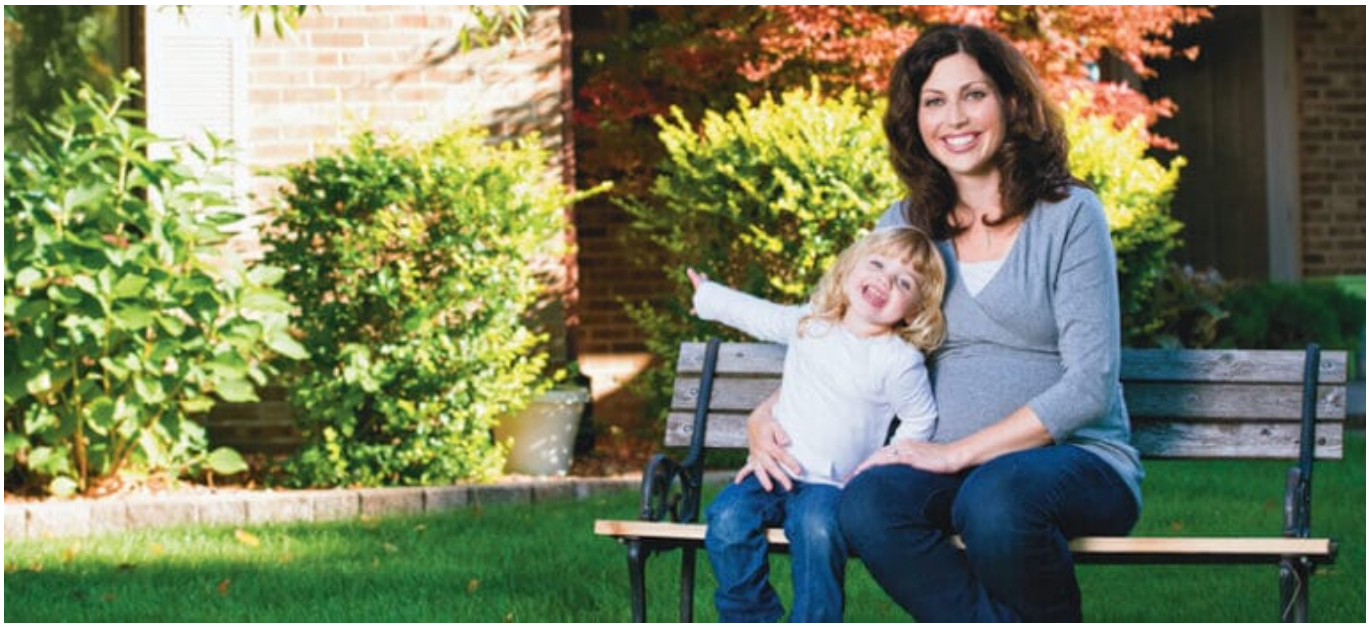
Pregnancy and MS

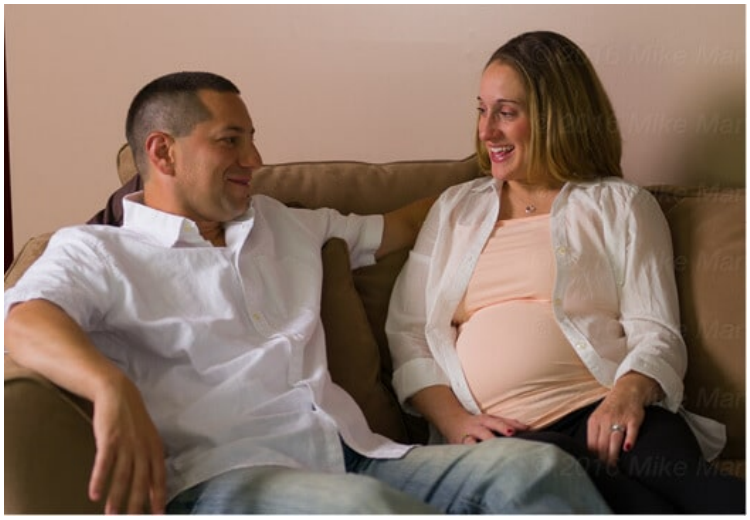


It’s natural to have concerns about pregnancy when you have MS, but most of what we know is good news.

by Aviva Patz

Jennifer Ganley was diagnosed with multiple sclerosis in October 2012, just a month before she and her husband were to celebrate their first wedding anniversary. “It was horrible,” says the 35-year-old pharmaceutical sales representative from East Hartford, Connecticut. Besides fearing for her health—and being afraid her husband of just one year might “run for the hills”—she was devastated to think she might not be able to start a family. “All my life I wanted to be a mom,” Ganley says. “I couldn’t bear to have the disease rob me and my husband of the dream we had for our future.”

People living with MS who are interested in starting or expanding their families are often justifiably concerned about whether it’s safe for them to become pregnant. They worry about whether pregnancy will worsen their MS and whether they’ll pass the disease on to their children.



Jennifer Ganley, with her husband, Jeff, felt "phenomenal" while she was pregnant. She was diagnosed with MS in 2012—right before her first wedding anniversary. Photo by Mike Marques

Had Ganley lived in an earlier era, her doctor may have advised against getting pregnant. "Up until the 1950s, we used to think pregnancy made MS worse, but it turns out that was completely wrong," says Dr. Patricia Coyle, director of the MS Comprehensive Care Center at the Stony Brook Neurosciences Institute at Stony Brook University. "Pregnancy has no negative effect on the MS prognosis, and many studies have hinted at a benefit."

If you have MS and are considering having a baby, here's what you need to know.

Could MS affect your baby?

Right off the bat, you're probably wondering about passing MS on to your child. "MS is not a directly inherited disease—there's no single gene that passes on MS," Dr. Coyle says. It's actually thought to occur due to a combination of genetic factors, environmental factors and immune factors. People with MS have a slightly increased risk of having a child develop the disease—it goes from 0.13 percent in the general population to between 2 and 2.5 percent if a parent has MS—but the risk is higher for a child who has a sibling with MS. This suggests a bigger role for environmental factors, Dr. Coyle says, explaining that siblings are exposed to the same environmental factors, whereas the parent grew up in a different environment.

You can also feel reassured that your MS will not cause any harm to your baby. "There's no evidence of worse outcomes for children of women with MS," says Dr. Nancy Sicotte, professor and vice chair for education and director of the Multiple Sclerosis Program at Cedars-Sinai Medical Center in Los Angeles. "In general, women with MS have normal, healthy pregnancies."

In addition, Dr. Sicotte says, there are no special considerations for labor and delivery.

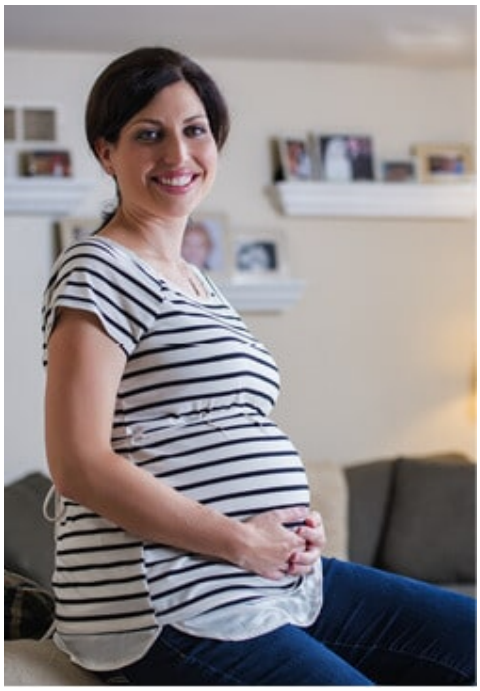
Women with MS are encouraged to follow the birth plan that works for them. “Standard epidurals are not a concern,” Dr. Sicotte says. And while spinal anesthesia may be a possible concern, that’s only because it could mean a prolonged recovery. It won’t worsen any existing damage to the spinal cord. “If you really need it—because of a high forceps delivery or other unusual intervention,” Dr. Sicotte says, “it’s probably better to get it.” Not all anesthesiologists are familiar with MS, however, so it’s a good idea for expectant women to speak with their anesthesiologists beforehand to clarify any concerns and discuss all potential options.

How pregnancy affects MS

The seemingly magical cocktail of pregnancy hormones tends to ease MS symptoms. “It’s pretty well known that MS improves during pregnancy—that’s been borne out by studies following hundreds of pregnancies,” Dr. Sicotte says. “There is a significant drop in relapse rates during the second and third trimesters—up to an 80 percent reduction in the third trimester.”

Ganley, who went on to become pregnant with her doctor’s blessing, remembers feeling “phenomenal” when she was pregnant, with much more energy than usual until the third trimester, when fatigue set in, as it does for almost all pregnant women, whether they have MS or not.

Rebecca Kuchar, of Livonia, Michigan, also felt great during her two pregnancies. “I got a break from the MS fatigue and the tingling,” says the mom of a 3-year-old and 10-month-old. “My cognitive function improved, I wasn’t tripping as much, and I had better control of my hands.” She adds, “I pretty much felt normal.”



Rebecca Kuchar. Photo

courtesy of the National MS
Society

There are two main theories for why pregnancy helps with MS symptoms. For starters, pregnancy leads to a shift in immune responses. “You’re carrying a baby that has half foreign DNA, from the father, so your immune system has to change in a way that makes your body less likely to reject the fetus,” Dr. Sicotte says.

The other theory focuses on the anti-inflammatory and seemingly neuroprotective power of pregnancy hormones. The National MS Society targeted this area of research in the 1990s, generating new information on sex differences in disease course, the immune system, brain tissues, hormonal influences and response to infection, and significantly increasing the number of scientists pursuing these questions in MS.

Though most of the impact of MS on pregnancy is positive, there are a few special concerns: During the third trimester, a woman who already has gait difficulties may find that her now-heavy belly shifts her center of gravity and makes balancing more precarious. In this case, using a cane or walker or even a wheelchair can be the safest way to go. It’s also possible that pregnancy will aggravate bladder and bowel problems for women who are already prone to them. Fatigue may also be worse for some women with MS, but many report feeling more energized than usual.

MS and the postpartum period

Goodbye pregnancy hormones, hello again, MS symptoms. Within three to six months after giving birth, the risk of a relapse spikes. While it was previously believed that 20 to 40 percent of postpartum women experienced a relapse, Dr. Coyle says recent data show the risk rises by only about 14 percent. Either way, postpartum relapses do not seem to worsen long-term disability.

Kuchar had a relapse at almost exactly the one-month mark. “I had uncontrollable vertigo,” she says. “I couldn’t walk, I couldn’t lift myself off the floor—the room was spinning constantly.” Only a combination of high-dose steroids, Antivert® (meclizine, a drug for dizziness and sleep problems) and lots of sleep helped ease Kuchar out of the relapse. Coincidentally, it was a month after Kuchar’s first delivery, three years earlier, that she was diagnosed with MS. “It’s not uncommon that people will have their first-ever MS attack during the postpartum period,” Dr. Sicotte says. “You’re definitely at higher risk.”

After the birth of her child, Ganley had been planning to hurry up and get pregnant again, so she wouldn’t have to go on and off medication in between, but her plans changed after her daughter’s first birthday. Ganley had stopped nursing her daughter at 11 months and had a “really bad” relapse three months later, causing debilitating numbness and tingling along the left side of her body. An MRI showed new MS-related lesions, and Ganley’s neurologist said it was time to go on medication, even if she took it for only a year before trying for another

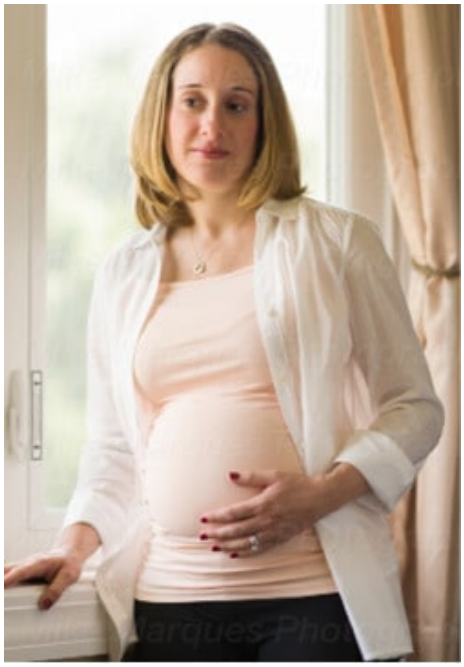
baby. “I thought, ‘Once I go on this drug, I’m not going off of it,’” Ganley says. “Why risk another relapse? My daughter’s best interest now is having a healthy mother.” While Ganley chose not to conceive again, the decision will be different for everyone depending on their circumstances.

Another postpartum concern is mood changes. Depression and anxiety are twice as common among people living with MS, so it stands to reason that postpartum depression might also be more common. In a 2016 study in the **Multiple Sclerosis Journal**, researchers from the University of British Columbia in Vancouver, Canada, found that new moms living with MS had a 28 percent higher risk of peripartum depression than moms without MS, and dads with MS had 2.68 times higher risk compared to dads without MS. “As a clinician, I’m always on the lookout for depression in my MS patients,” Dr. Sicotte says. “And the postpartum period adds a layer of vulnerability.”

Before conceiving

The FDA and medical experts agree that if you’re pregnant or trying to get pregnant, you should not be on DMTs or any other treatments that could have an impact on pregnancy.

However, newer data suggest that two classes of therapies may be safe to continue: glatiramer acetate, an injectable medication that helps prevent relapse (and is available as Copaxone® and its generic equivalent, Glatopa™), and interferon betas (including Avonex®, Betaseron®, Plegridy® and Rebif®). “We don’t have clear data, but there have been multiple trials with hundreds of women and there’s been no evidence of fetal harm,” Dr. Coyle says. “Lots of exposures and no issues means you probably don’t need a wash-out period with those two classes of treatments.” Talk to your doctor about the new evidence and whether it’s safe for you to continue with those therapies.



Jennifer Ganley. Photo by Mike

Marques

You might also be able to keep taking some of your symptom-management medications, like those used for severe depression. Talk to your neurologist about the risks and benefits of any medication, and how they affect your particular circumstances, Dr. Sicotte suggests. And if you do decide to continue taking a medication, the lower the dose, the better.

For women who haven't yet started disease-modifying therapy and are trying to decide whether or not to try to conceive first, there are compelling new findings to consider: "Data from the most recent MS-based registry show that if someone has active MS and they go on treatment and later become pregnant, they have a significantly lower risk of postpartum relapse," Coyle says.

This has actually led her to change how she counsels patients. "Now if I have a newly diagnosed patient who wants to start a family and asks, 'Should I get pregnant now or should I go on DMT for a year or two?' I'm going to recommend the DMT and hold off on the pregnancy if I'm at all worried about the patient," Dr. Coyle says. "We're learning that it may be better to get the disease under control first—to reset the thermostat, as it were."

You'll also want to discuss a game plan for the unlikely event of a clinical attack during pregnancy. It may involve a short course of high-dose steroids, which Dr. Coyle says shouldn't be a problem, especially if you use the type of steroids that are known to not cross the placenta. Solu-Medrol (methylprednisolone), the most commonly used steroid, is metabolized before it passes the placenta, as is high-dose prednisone, says Dr. Coyle, who cautions against using dexamethadone.

Your age and MS

Up to 97 percent of women with MS looking to get pregnant have the relapsing-remitting form of the disease, and are typically on the younger side with milder symptoms, Dr. Coyle says. It gets more complicated for women who are older or who have more disease activity.

"For women over 35, we're concerned that it could take longer to conceive, which raises the risk for relapse," since they will be off their DMTs for longer, Dr. Sicotte says.

"For more disabled women, there can be issues of comfort during pregnancy to consider, as well as concerns about how they choose to deliver, because it could take longer to recover from a C-section."

So if you're considering starting a family, Dr. Sicotte says to go for it as soon as possible, once your disease is well controlled. "You may end up trying to have children earlier than you might have otherwise," she says. "But that could be what's safest for your health."

MS and breastfeeding

Just like with pregnancy, breastfeeding is a time when it's considered unsafe to take DMTs,

because no one knows whether the medications are excreted into breast milk.

But also, just like with pregnancy, breastfeeding seems to improve MS symptoms. In a pivotal 2009 study published in **JAMA Neurology**, women who breastfed exclusively—that means less than one bottle of formula a day—had a lower risk of relapse. Of the participants with MS who did not breastfeed or who supplemented with one bottle or more of formula daily after two months, 87 percent had a postpartum relapse, compared with 36 percent of the women with MS who breastfed exclusively for at least two months. The researchers, from Stanford University School of Medicine in California and Kaiser Permanente of Northern California, believe these findings call into question the benefit of forgoing breastfeeding to start MS therapies earlier, though these results should still be confirmed in a larger study. “Keep in mind that exclusive breastfeeding is a very different physiologic experience than doing some nursing, some formula,”Dr. Sicotte says, because when you’re nursing exclusively, you typically don’t menstruate or ovulate.

Kuchar, who is still exclusively nursing her second child, gets monthly IV infusions of steroids, and then she’ll “pump and dump” her breast milk for 24 hours so there’s no chance of the drug reaching her baby. She’s also getting MRIs every month so her neurology team can closely monitor her disease progression while she’s off medication.

“I very much encourage women to breastfeed for as long as they want to,” Dr. Sicotte says, acknowledging that women who choose to breastfeed are probably those with milder disease activity. “For some women,” she adds, “the fear of relapse is significant enough that they immediately get back on their medication.” Dr. Coyle puts it more strongly: “If I’m worried about my patient, I prefer them to go back on their disease-modifying therapy and not breastfeed, since I doubt breastfeeding is as effective as a high-efficacy DMT.”

Ganley wishes she had gone on medication immediately after exclusive breastfeeding, instead of staying off meds in order to try to conceive again. “Knowing how awful I felt and what a challenging time it was for my family and with my daughter so young, I feel like I played roulette with my health,” she says. “The disease is unpredictable—there’s no crystal ball to tell you when a relapse is coming.”

But life, too, is unpredictable, so if starting a family has always been part of your personal plan, there’s no reason not to move forward. “Pregnancy fits with the whole way we now see MS—as a manageable, chronic disease,” Dr. Sicotte says. “Just because you have this diagnosis doesn’t mean you can’t bear a child and raise a child. Live the life you want to live and don’t let MS hold you back.”

Aviva Patz is a freelance writer in Montclair, New Jersey.

For more information on pregnancy and MS, visit Pregnancy and Reproductive Issues and Hormones and gender under the microscope.

Discuss your experiences and thoughts about pregnancy and MS with others at MS Connection.