



Family Planning & Multiple Sclerosis

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Living with MS

MSology Essentials Series

Family Planning & Multiple Sclerosis

Women's Health Series

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Introduction

Multiple sclerosis (MS) is the most common neurological disorder affecting young women. It's typically diagnosed when a woman is in her twenties or thirties – just when there are important decisions to be made about starting a job, finding a partner and having children.

If you're living with MS, it doesn't mean that you can no longer become pregnant, breastfeed or raise a child. But your illness, and the medications used to treat it, will need to be considered as you make decisions about your future.

This booklet, the first in a series on women's health issues, has been developed in collaboration with nurses specialized in MS to answer some of the most common questions about pregnancy and breastfeeding. Having a child is a very personal decision for you and your partner, but it's essential to discuss your plans with your doctors and MS clinic nurse before you become pregnant. Decisions will need to be made about managing your MS and your medication regimen in the months before you become pregnant and after the delivery to ensure the health of you and your baby.



MS relapses are usually less common during pregnancy. This is believed to be due to the hormonal changes that occur.



Does MS affect my ability to get pregnant?

A number of studies have suggested that MS does not affect a woman's ability to become pregnant or to carry a healthy baby to term. Women with MS don't appear to have a higher risk of infertility, spontaneous abortion, complications during the delivery or birth defects compared to women in the general population.

Will my baby get MS?

A common concern for people with MS is whether they'll pass their illness along to their children. Genetic factors do influence your risk of developing MS, but no "MS gene" has been identified. Rather, genetic and environmental factors appear to affect a person's susceptibility to MS and how the illness develops over the course of your lifetime.

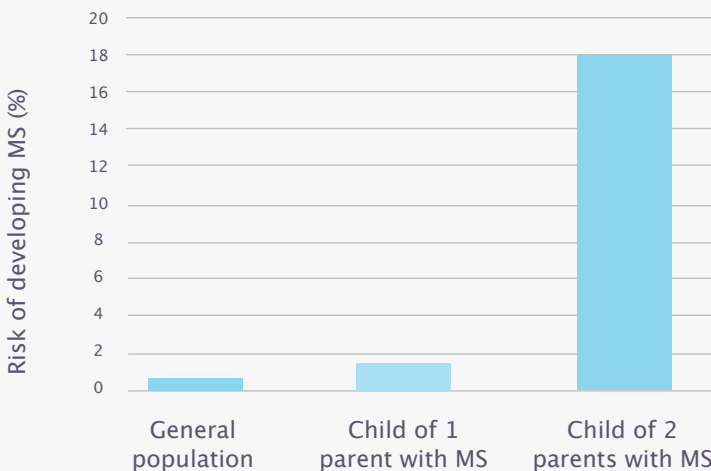
This means that MS is not inherited, in the way that some genetic diseases (such as cystic fibrosis) are heritable. Babies are not born with MS, so there's no test during pregnancy (such as amniocentesis) that's able to determine whether your child will develop MS later in life.



For MS to develop, genetic and environmental factors must interact in complex ways that are not well understood. The genetic factors – largely unidentified – that contribute to a person’s susceptibility for developing MS can be passed along, which may increase your child’s MS risk in later years.

But this MS risk is very small. If both you and your partner have MS, there is a 1 in 6 chance that your baby will develop MS at some point in their lifetime. If only one parent has MS, the risk is much smaller – about 1 in 50.

Lifetime risk of developing multiple sclerosis



There is a low risk that MS will develop in babies born to mothers with MS. Environmental factors will also affect a child’s risk of MS.

Adapted from O’Gorman and colleagues. *Neuroepidemiology* 2013; 40:1–12



What happens to my MS during pregnancy?

MS is a disorder in which immune cells become abnormally activated, causing inflammation and tissue damage in the brain and spinal cord. These inflammatory flare-ups interrupt the normal signalling of nerve fibres, and cause tingling, numbness, nerve pain, muscle weakness and other MS symptoms. Episodes of worsening symptoms that persist for 24-48 hours are called *relapses*.

Pregnancy causes hormonal levels to change, which in turn alters how your immune system functions. One change is that your immune system becomes less reactive – in part to protect the developing fetus. A consequence is that you may become more susceptible to colds or other infections during your pregnancy. But another consequence is that your MS typically becomes less active. This is especially true during the third trimester. In these last three months of your pregnancy, you're less likely to have an MS relapse.



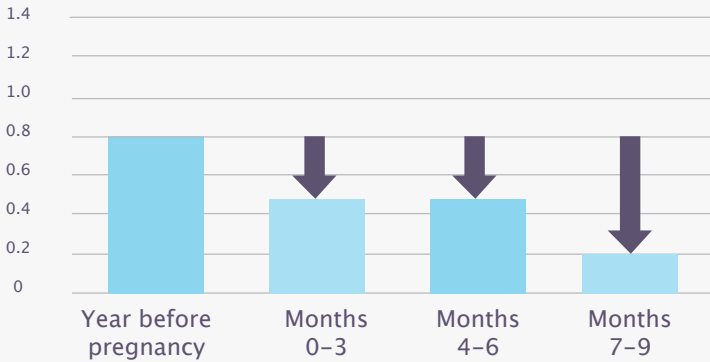
What happens to my MS after childbirth?

The risk of having a relapse increases in the first three months after childbirth. This is a concern if your MS was very active in the year before you became pregnant. There's some evidence to suggest that this flare-up in your MS symptoms can be delayed if you exclusively breastfeed (i.e. no bottle feeding). But after the baby is weaned, there's a risk that your MS will become active once again. About 3-6 months after childbirth, the symptoms and severity of your MS typically return to how they were before your pregnancy.

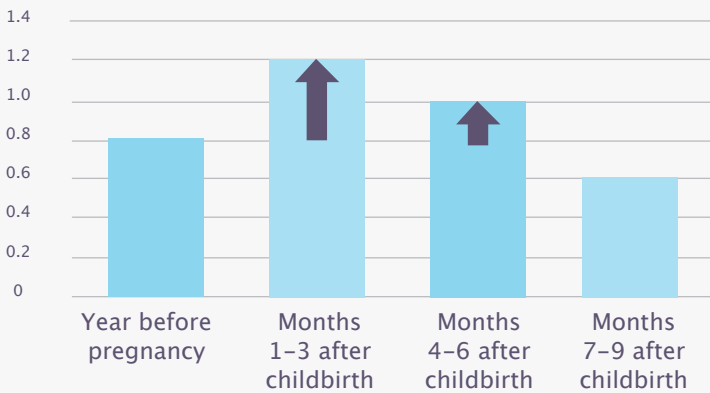
The short-term flare-ups of MS activity that can occur after pregnancy don't appear to have an impact on the long-term course of your disease. Pregnancy is not believed to affect your chances of developing disability later on. However, it's important to consider that a short-term worsening of your MS – a relapse, MS fatigue or other symptoms – can be an added challenge in those early months of feeding and caring for your new baby. So it's often best to re-start your MS medication as soon as possible after childbirth.



Risk of having a relapse during pregnancy



During pregnancy your risk of having a relapse goes down



After your baby is born, your risk of having a relapse goes up

Relapses become less frequent during pregnancy. However, there is a higher risk of having a relapse in the first trimester (three months) after childbirth. Adapted from the Pregnancy and MS (PRIMS) study.

Vukusic and colleagues. *Brain* 2004;127:1353–1360.



Planning your pregnancy

When to start a family or to have another child is an important decision, and a diagnosis of MS can make that discussion seem all the more urgent. Should we have a child right away before my MS gets worse? Should I keep working to build our finances before we get pregnant? Or should we wait until treatment gets my MS under control before we try to get pregnant?

There's no right or wrong answer to these questions. What is best for you will depend on your circumstances – your personal desires, your relationships, your employment and financial situation. You can find the best solutions – but it'll take some planning. So it's best to discuss your options with your partner, family and friends, your neurologist and your MS clinic nurse.

Talking to your MS nurse about your plans

Your MS nurse can help you meet your needs both as a woman who wants to become pregnant and as a person with MS. But to ensure that these two needs are met, your nurse will need to know your plans.



What's important is to weigh what's best for you now. Treating your MS as soon as possible is important to bring the disease process under control. On the other hand, it's best to be taking no medication during your pregnancy. So your plans for pregnancy will determine your treatment plan.

For example, if you are actively trying to become pregnant, or want to get pregnant within the next few months, it may be best to delay treating your MS so you are drug-free at the start of your pregnancy. It's also best to be drug-free while you're breastfeeding. So when your baby is born, you'll need to decide how long you want to breastfeed. You can then schedule to start your MS medication once your baby has been weaned. The timing of these decisions will depend in part on your MS: if your MS is active and you're experiencing disabling symptoms, it may be best to start treatment as soon as possible.

Alternatively, if your MS is more active, or you're planning a pregnancy in a few years, it may be best to start treatment right away. Some studies have found that women who go on treatment for a couple of years are less likely to have a relapse after they do have a child. So taking an MS medication can help you achieve your goal of being as healthy as possible as you start to think about pregnancy. But continue to use a reliable form of contraception in the meantime so you won't have to interrupt your treatment because of an unplanned pregnancy.



5 Tips for Planning Your Pregnancy

- 1** Be as healthy as you can be. Exercise regularly, quit smoking, avoid junk foods and get enough sleep. Talk to your obstetrician-gynecologist about the vitamins and supplements (e.g. folic acid) you'll need.
- 2** Drink water regularly to ensure you are well hydrated – especially after exercise. Overheating can worsen your MS symptoms.
- 3** Investigate the maternity benefits to which you're entitled (e.g. income, time off work, reintegration after maternity leave).
- 4** Discuss your plans with your family doctor.
- 5** Discuss the timing of your pregnancy with your MS care provider – before you get pregnant! You'll need to make some decisions about how best to treat your MS.



A reliable form of contraception should always be used until you and your MS care provider have discussed your pregnancy plan.



5 Tips After your Baby is Born

- 1** Maintain your wellness – eat well and stay hydrated.
- 2** Try to avoid getting overtired. Childbirth can worsen your MS fatigue.
- 3** Ask for help – from your partner, family and friends. You'll need to take a break if you're troubled by any MS symptoms.
- 4** Talk to your family doctor or obstetrician if you're feeling depressed or anxious.
- 5** Talk to your MS care provider about how long you plan to breastfeed, and when you should start taking your MS medication.

Contraception

If you are taking an MS medication, it's essential for you and your partner to use effective contraception to prevent any unplanned pregnancies. It's important to note that oral contraceptives (birth control pills) may not be the best choice since they can be less effective if you are taking certain MS medications. Talk to your family doctor about the best methods for preventing pregnancy.

Continue using your method of birth control until you have talked to your neurologist or MS nurse about your pregnancy plans.



Recommendations for contraception while on an MS medication

Medication	Need for contraception?
Beta-interferons (Avonex/ Plegridy, Betaseron/Extavia, Rebif)	Yes
Copaxone	No recommendation Use during pregnancy only if clearly needed
Gilenya	Yes
Aubagio	Yes
Tecfidera	Yes
Tysabri	No recommendation Use during pregnancy only if the potential benefit justifies the potential risk
Lemtrada	Contraception needed during treatment and for 4 months afterward



When should I stop taking my MS medication?

Many drugs have the potential to harm a developing fetus, so it's best if you're not taking any drug – including the medications used to treat your MS – when you first get pregnant.

While MS treatments are needed to control your illness, they generally must be stopped well before you start trying to get pregnant. This is because some MS medications can take several weeks or months to disappear from your body. The safest option is to continue using an effective method of contraception, and talk to your neurologist and MS nurse **before** you try to get pregnant. This will enable your physician to stop your medication beforehand, ensuring that your body is drug-free throughout your pregnancy.

If you learn that you are pregnant while taking an MS medication, call your MS clinic immediately. The clinic will advise you on stopping your treatment, and any other procedures that may be necessary. Using an MS medication during pregnancy can have serious consequences. So your clinic will also want to book an appointment with you so you can talk about the risks and what are your best options.



5 Common myths about MS, pregnancy and breastfeeding

Myth	Fact
1. Women with MS should not get pregnant because it will worsen their illness.	<ul style="list-style-type: none">• Pregnancies will not influence the amount of MS-related disability that may develop.
2. Women with MS are likely to pass the disease along to their baby.	<ul style="list-style-type: none">• About 98% of babies born to women with MS do not develop the disease later in life.
3. Women with MS are unable to care for a baby.	<ul style="list-style-type: none">• MS symptoms can be difficult at times. But it will not stop you from loving and caring for your baby.
4. You need to stop taking your medication as soon as you learn that you're pregnant.	<ul style="list-style-type: none">• It's best to stop your medication a few weeks or months before you get pregnant. Medications can stay in your body even after you stop taking them, so you'll want to ensure that your body is drug-free when you get pregnant.
5. Women with MS can't breastfeed.	<ul style="list-style-type: none">• MS does not affect a woman's ability to breastfeed.• The choice to breastfeed is a very personal one and will depend on your wishes.• MS can flare up after childbirth, so it's sometimes best to go on your MS medication as soon as possible.• You will need to wean the baby before you re-start treatment because some medications can accumulate in breast milk.• Your MS nurse can advise you about when and how to re-start your MS medication to ensure the health of you and your baby.



Assisted reproduction

MS doesn't appear to affect a woman's fertility. However, older women and those with certain medical conditions may find it more difficult to get pregnant. One option is to use assisted reproductive technology, such as in vitro fertilization (IVF).

IVF has been used successfully in many women with MS. There is no indication that IVF is less likely to work in women with MS compared to other women of the same age. However, it's important to note that IVF involves the administration of hormones that can affect your MS.

If IVF is successful, your risk of an MS relapse will decline during your pregnancy, just as it would during any other pregnancy. However, your risk of relapse will increase if the IVF procedure fails. This is due to the hormones, as well as certain medications used to stimulate hormone production, that are administered as part of the IVF procedure. If you are planning to try IVF, ensure that your obstetrician-gynecologist knows about your MS before you start taking the IVF regimen.



Questions to ask your MS nurse



Contacts

MS clinic: _____

Family physician: _____

Obstetrician/gynecologist: _____

Other numbers: _____





The MS Essentials series provides the latest information on multiple sclerosis medications, research, and lifestyle issues such as health, nutrition and exercise. All of the booklets are developed by Lind Publishing, publishers of MSology, to help people affected by MS remain active and informed.

MS Essentials is provided free of charge. The full series of publications is available for download at www.MSology.com



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