

Parenthood and MS:

Arriving at a decision that works for you

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It's common for individuals in their twenties or thirties to consider if and when they will have children. It's a big decision! Add multiple sclerosis to the mix and many women – and men – can feel overwhelmed.

The choices have immediate implications, but also long-lasting ones as babies grow into children, then teenagers. What is the right thing to do? And how can you plan with a disease as unpredictable as MS?

Multiple sclerosis can be diagnosed at any time in life, from childhood to late adulthood, but for most people the first symptoms occur between the ages of 15 and 40 – the time when people are finishing school, starting careers and planning families.

The good news is that there is no right or wrong answer about parenthood and MS. Decisions about whether or not to have children will be as individual as you are. Factors such as fatigue, your current physical status, and the course of your disease will be a part of your deliberations.

Let's face it: going through pregnancy and delivery, and then raising a child, is mentally and physically exhausting whether or not MS is a factor. But often these issues seem trivial to women and men who want a child to hold and nurture for years to come. This feeling is no different for people with multiple sclerosis. After all, multiple sclerosis does not impact the parental instinct or the ability to be loving and caring.

"I had some reservations about becoming a parent... We [my husband and I] debated on what to do and decided to try for children. Facing a future without children just seemed implausible to me," says Judith Cooper, a mother of two, ages 10 and 14, who lives in Dauphin, Manitoba.

The physical limitations sometimes associated with MS mean that people who are considering starting a family must plan ahead. It is imperative to have the appropriate support (spousal, family, professional), routines and equipment in place to ensure MS does not either impede the parenting experience or be detrimental to the health and safety of both the parent with MS and the child.

"I was always frightened to hold my daughter in case I dropped her or fell, so I got a bassinet that had wheels on it so I could wheel her everywhere with me," says Andrea Butcher-Milne of Barrie, Ontario, whose daughter is now six. She was diagnosed with MS in 1997.

Women and men with multiple sclerosis who are considering having a child should ensure all their questions and concerns are addressed by appropriate healthcare professionals including a neurologist, physician / midwife who will supervise the pregnancy and delivery, MS nurse, occupational therapist (to assist with adaptations to the home) and genetic counsellor.

There are numerous questions ranging from



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becoming pregnant, managing the pregnancy and labour and then extending to parenting itself. While each individual and couple have unique situations in respect to MS and life circumstances, the following questions and answers can provide the basis for further discussion with your partner and/or physician.

Can MS be passed to my child?

There is a slightly increased risk that children of parents with MS might develop the disease compared to the general population. The risk varies depending upon factors such as the number of family members with MS and whether MS is on both the maternal and paternal sides of the couple.

However, in up to 80 percent of families, one parent is the only family member to have MS and thus the risk their child will develop MS over their entire lifetime is approximately three to five percent. While this risk is higher than the general population risk of 0.2 percent, it is still very low. Put another way, there is over a 95 percent chance that your child will not develop MS.

How will MS impact my pregnancy?

Many women with MS experience a remission of symptoms during pregnancy, especially during the last three months, although this can depend upon the clinical course of MS the woman is experiencing at the time of conception.

“Pregnancy was the best I ever felt,” says Judith Cooper. “I think my emotional state of being so happy contributed to me doing so well.”

However, there appears to be a higher risk of MS relapses within three to six months of delivering the child, but again this varies. “During pregnancy I didn't have any clearly defined attacks,” says Andrea Butcher-Milne. “Six months after my daughter was born my MS symptoms actually got worse so I went on one of the disease-modifying drugs and that really helped.”

The possibility of an MS relapse following the birth of the baby should be planned for so

that you have the appropriate assistance in place to help care for the baby while you recuperate from the relapse.

It makes sense to talk to a physician (probably an MS neurologist) who has expertise treating MS symptoms and relapses and who is knowledgeable about the safety of specific drugs and other exposures during pregnancy.

Overall, having good support from your healthcare team during this period is essential. That team will probably include your obstetrician, family doctor, midwife, neurologist and MS nurse.

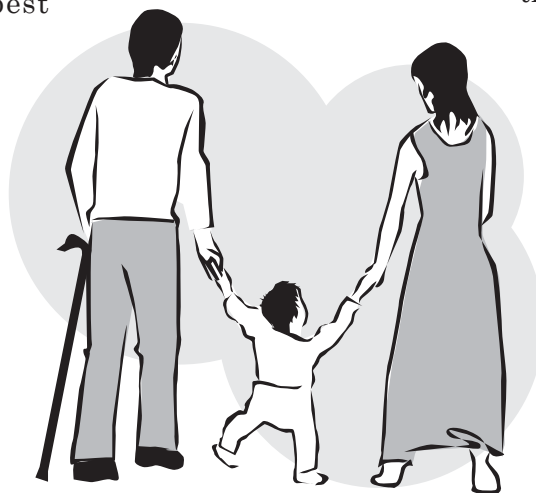
Is it okay to have an epidural during labour? What will labour be like?

There is no definitive answer to either of these questions. Labour is an individual experience. Fatigue should be taken into account, as labour can be very exhausting. Discuss fatigue with your physician and ask what options and support will be available to you if you become too tired during labour.

“My first delivery was natural; the only drugs I received were Demerol and another drug to numb the area for the episiotomy. I was in labour 23 hours and was treated as a high-risk patient due to my MS,” recalls Judith Cooper. “My second labour was C-section because I was stuck at 5cm [dilation] for almost 15 hours and was very tired.”

If you choose to have an epidural anesthetic to block the pain, again plan ahead and have a discussion with your doctor as to whether the procedure is right for you. Keep in mind that some anesthesiologists will not administer an epidural to a woman with MS because it means inserting a needle into the epidural space of the spine. Make sure the hospital where you plan to deliver has an anesthesiologist willing to administer

one, if that is your decision. You should also be aware that some women – totally unrelated to MS – encounter problems with the procedure such as low blood pressure, headaches, allergic reaction and/or relaxation of the muscles needed to push – meaning assistance is required to deliver.



Other methods to help with labour include using various breathing techniques of which the Lamaze method is probably the best known. An epidural relieves pain while Lamaze involves acknowledging the pain and using breathing methods to manage it. It also teaches effective pushing methods to help deliver the baby.

Based on your physical ability, you and your doctor or midwife should decide which is best for you. A woman should not be categorized as having a “high-risk” pregnancy solely on the basis of having MS. Keep as many options open as possible. The goal is to ensure the safest delivery for

Dads have MS too: What men need to consider

A lot of the issues that women experience can be applied to men, especially in the age of co-parenting. But there are a few differences.

Medications: According to Gwen Alcock, MS nurse and coordinator of the St. John's MS Clinic in Newfoundland and Labrador, “Most men make the decision to come off their therapies, particularly the disease-modifying therapies, when they are trying to conceive with their partner.” Talk to your physician about this decision and ways to manage MS while you are trying to conceive. A man also has the choice of freezing sperm before starting treatment.

Labour: MS fatigue may stop you from being with your partner through all the hours of labour, but you can still provide important emotional support. You and your partner could consider having a close family member and/or friend spend part of the labour with your partner while you take a break. Finding a balance and using the support and resources available are important skills to learn for both labour and the years to come.

Child care now and in the future: Finances, the physical status of the partner with MS, and the needs of the child may dictate who is responsible for primary child care. Discuss this openly and continue to do so as your MS and the child's needs may change over time. Also, don't be surprised if some stereotypes about male roles and parenthood arise – these can be emotionally ingrained rather than logical. Remember, a father does so much more than teach his child to ride a bike.

Talk your expectations through with your partner and keep a perspective about all the different ways someone is a parent.

both mother and child.

Judith Cooper found it helpful to learn as much as possible in advance. “We took the pre-natal classes, saw the film on labour, did the stretches, the breathing and the coping techniques.”

Some women with MS – as well as women who do not have MS – have C-sections if problems develop during labour. It is smart to plan for this possibility since a C-section requires more recovery time – sometimes up to several weeks. Both Andrea and Judith had C-sections and were able to turn to family for assistance while they recovered.

Can medication for MS be used during pregnancy and breastfeeding?

There are no clear-cut answers to this questions since at present data is limited. Generally women are advised not to continue the disease-modifying therapies when planning to conceive, during pregnancy and while breastfeeding. (See the article on page 10 for the results of one recent study, *Beta interferon therapy use during pregnancy*.)

This is an issue for Danielle of Nova Scotia, who is considering becoming a mother. “My biggest concern about having children is that I would have to come off my medication,” says Danielle, who is 25 and was diagnosed in 1993. “I've been taking [one of the therapies] for seven years, and it works for me. If I have a child, I could be off my meds for almost two years.”

Again, planning ahead is key. Ideally, a woman who wants to become pregnant should stop the disease-modifying therapy (and other medications as indicated by her physician) before becoming pregnant. She should remain off the medications during the pregnancy and then resume them following delivery, if she is not planning to breastfeed the baby. Another good strategy is to have a discussion with your neurologist or MS nurse about ways to manage MS during pregnancy and breastfeeding.

Andrea Butcher-Milne followed this advice. “I wasn't on any medication before I got pregnant. I decided to wait until I had my child before I began to take medication for MS,” explains Andrea. “I didn't want to go on meds for a bit and them come off for several years and go back on.”

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What about fatigue and parenthood?

Fatigue is an all too familiar symptom for people with MS as well as for mothers taking care of a newborn. A baby's needs can't be placed on hold so methods and routines to manage fatigue need to be developed to ensure you can care for your baby. Consider extra help with household chores, sleeping when the baby sleeps, and enlisting help when the baby is fussy. Getting as much rest as possible is the key to keeping up with your baby's needs, and your own.

"You are definitely going to get fatigued so plan ahead once the baby is born," cautions Andrea. "Plan to take twice as much time to finish a household chore than before you had a baby to take care of. It may not take twice as long but give yourself that time frame in case it does."

It is wise not to wait and see if you can handle a baby and MS fatigue. Instead, you and your partner should have the resources and support in place before the baby is born. For example, you can organize family and friends to help out several times a week. Or you may be able to hire a housekeeper to take over household chores for a period of time.

While adjustments may have to be made, parenthood is a viable option for most women and men with MS. Adjusting for physical limitations, fatigue and other MS symptoms is part of the challenge of living with this disease. Children need love and support, and you can provide those things regardless of MS. Focus on what you can do – rather than on what you cannot do!

"Children take a lot of resources, a lot of money and a lot of patience – a lot of everything!" exclaims Judith. "But they give you a tonne in return."

"Absolutely go for it," Andrea adds.

Gemma Graham's mother has MS and this subject is very close to her heart. She adds, "As someone whose mother had MS while I was growing up, I can confidently say that my mother was no less capable of raising two children than any other woman."

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Beta interferon use during pregnancy linked to miscarriage, low birth rate

In September 2005, researchers at SickKids Hospital in Toronto reported that women being treated for multiple sclerosis (MS) with beta interferon therapy have an increased risk of miscarriage or low infant birth weight.

The research strongly suggests that women with MS who become pregnant while taking beta interferon should contact their physicians about discontinuing the drug until delivery. In addition, women who are considering becoming pregnant and are using beta interferon therapy should talk to their physicians about how long they should discontinue therapy before becoming pregnant.

The research team found that continued use of beta interferon therapy through pregnancy resulted in a 39 percent increase in miscarriages, a 30 percent increase in non-live births and a lower overall birth weight in live births compared to women who stopped therapy and to healthy controls.

"Most importantly, we recommend that women with MS who are pregnant or planning on becoming pregnant speak with their neurologists. Discontinuing beta interferon therapy during gestation should not necessarily increase the risk of relapse of MS, as pregnancy tends to reduce such risk," says Dr. Gideon Koren, the study's principal investigator. The researchers also recommend women with MS resume interferon therapy very soon after delivery if they do not intend to breastfeed.

For more information, see the medical update on the MS Society website (www.mssociety.ca – go to Research and then Research News).

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See page 4 about the new pregnancy registry project.