



MS and Family Planning

For people living with MS

Starting a family can be a big step in a person's life, no matter who you are. However, being diagnosed with MS may leave you with extra questions about planning for a family.

This booklet gives you advice on starting or growing your family while living with MS. For some sections, there are different parts which you may find are more relevant if you are pregnant or if your partner is pregnant.

If you need them, your MS team and specialists are there to support you along the way and can provide you with expert guidance.

Starting a family

Should I discuss plans to start a family with my MS team?

Family planning for people with MS can be a journey that often begins at diagnosis.

It's a good idea to discuss family planning and your treatment plans with your doctor as soon as possible after diagnosis to ensure your future goals can be met.

Your MS and how it is treated will be important to consider. This is true for men with MS who want to father a child, women with MS who want to mother a child, and people with MS who want to adopt or foster.

Are there any concerns about having a family?

Some people may have concerns about starting a family, no matter who they are. As a person living with MS, you may feel worry or guilt around your choice to have children.

It's important to remember that people with MS can raise and care for a family just as well as people without MS. If you are having any doubts, do speak with your doctor or MS team.

REMINDER

MS isn't directly passed on ('inherited') from mothers or fathers with MS. However, the risk of developing MS is higher in siblings or children of a person with the condition compared with the general population.¹



Will MS be passed on to my child?

MS is not directly passed from parent to child, and it shouldn't prevent you from planning to start your family. While MS is not inherited, there is an inherited risk of developing it.¹



When a parent has MS

98%

of children **WILL NOT** develop MS²



When both parents have MS, approximately

80%

of children **WILL NOT** develop MS²

You can find more about the potential causes of MS in our *'Understanding MS'* booklet.

Can I adopt or foster a child?

Choosing to adopt or foster is a big decision to make and can transform the life of a child. Receiving an MS diagnosis does not immediately stop you from fostering or adopting. However, your health, including any long-term conditions, may be considered when applying.³

The most important thing is that you are physically and mentally able to cope with the demands of caring for a child.³ You can speak to your local fostering and adoption organizations for more advice.

Fertility

Will MS affect my fertility?

There is no evidence that MS affects the fertility of either men or women.⁴ Therefore, if you are not planning to start a family, you or your partner should use contraception. Whichever form of contraception you choose is up to you and your partner.

You should be aware that some treatments for MS may impact fertility.⁵ If you have any concerns or questions about this, you should speak with your doctor.

Is fertility assistance an option?

Some couples find they have trouble becoming pregnant. If you or your partner are experiencing this, there are some options to consider. These include IVF ('in vitro fertilization'), intrauterine insemination, and egg and/or sperm donation.

There may also be fertility treatments or surgeries that could help. Talk to your doctor to see if this could be an option for you.

REMINDER

Fertility issues can happen to anyone – there is no evidence that MS has a direct effect on fertility.⁴



Sex and relationships

What effect can MS have on sex?

You may find that MS and/or MS treatment affects your sexual feelings or responses. This is true for both men and women. This is entirely normal, and there are things that can help.

You may find you experience:



Low or no sex drive
(reduced 'libido')



Difficulty or inability
to get an erection



Numbness, pain or
high sensitivity



Difficulty or inability
to ejaculate



Decreased vaginal
lubrication

As a person living with MS, you may also experience fatigue, muscle spasms, loss of bladder and/or bowel control, and difficulty reaching orgasm. All of these can have an effect on your sex life.

What can help with these symptoms?

There are some things you can do to help. If you are worried about incontinence, try going to the toilet before intercourse. If you experience dryness, lubricating jelly can be useful for both you and your partner.

For men, there are some treatments that can help with getting and maintaining an erection. Although there are no medicines that help with ejaculation or orgasm at the moment, fertility clinics can provide advice if you have this issue.

You can also discuss any of your sex-related issues with your doctor.

How may MS affect how I feel about sex?

Some people with MS may feel less sexually attractive and less confident than before having MS. If you feel this way, remember MS does not define you – you are still you and attractive to others.

When it comes to sex, it is important to understand your own body and to also keep it enjoyable. Try to be open and honest with your partner, and be prepared to try different things – communication is key.



Talking steps

Step 1:

Get comfortable talking about 'it'

Talking about your sexual needs or preferences with your partner may help to relieve feelings of stress and anxiety. It can also deepen intimacy.

Step 2:

Talk to your MS team

Many sex problems related to MS can be managed with the right treatment.

Step 3:

Speak with specialists

Your doctor may refer you to other specialists such as a psychologist, urologist, sex therapist, and/or gynecologist. You can discuss intimate issues with them and work together to find solutions.



Trying for a baby

Should MS be controlled before trying for a baby?

It is especially important for women to have MS under control before becoming pregnant. Sometimes this is recommended for at least 1 year. Research shows that women with stable MS before pregnancy may have a lower chance of MS relapses after birth.⁶ Please discuss treatment options with your doctor.

For men, it is best to speak with your doctor about any preparation or changes you may need to make when trying for a baby.

Will I have to stop my MS treatment while trying to conceive?

Some MS treatments may cause harm to unborn babies, including at the time of conception, and others may not cause any harm. Please discuss treatment options with your doctor.

Because of this, your doctor will help you manage your MS before and during the time when you are trying for a baby. It is important to keep open communication with your doctor about your MS treatment and pregnancy.





Will it take longer to conceive because of my MS?

Trying for a baby can be difficult for anyone. Having MS does not directly affect your chances of conceiving.⁵

However, your MS symptoms or treatments may have an impact. This can include a wash-out period in which you need to stop treatment for a set length of time before attempting to conceive. The length of wash-out period, if needed, varies between treatments. Longer washout periods may increase the likelihood of symptoms becoming worse during this time.⁸ Talk with your doctor as early as possible about how you can increase the chances of conceiving.

What if I have a washout period with treatment and I relapse during that time?

As with all relapses, if you think you are having one, contact your doctor or nurse as soon as possible.

What if there is an unplanned pregnancy?

Nearly half of all pregnancies in the general population are unplanned.⁹ If you find yourself in this position, you should talk openly and honestly with your partner about next steps. Do speak with your doctor as soon as possible to make plans that are best for you.

During pregnancy

If you are pregnant

What support might I need during pregnancy?

Like all new parents, good preparation and a support network will ease the challenge of bringing up children. This is particularly important when one parent has MS. In general, having MS does not significantly increase the risk of having problems during pregnancy.¹⁰

Does pregnancy affect MS?

Pregnancy does not speed up the progression of MS. Pregnancy can even have a positive effect – the number of MS relapses can fall during pregnancy, especially in the third trimester (the last 3 months of pregnancy).¹¹ This may be related to the change in hormone levels that happens during pregnancy.⁶

However, after pregnancy there is an increased chance of MS relapses for some women.¹²

You can read more about this in the 'After delivery' section of this booklet.

What if I relapse during pregnancy?

A relapse during pregnancy is not thought to affect the baby. As with all relapses, if you think you are having one, contact your doctor or nurse as soon as possible. You may be able to still receive certain medications to help you cope during relapses when pregnant.

How will pregnancy affect my body?

As with any pregnancy, women with MS may get more tired, experience bowel or bladder problems, and find that their balance and walking is affected. This may feel worse if you already experience fatigue. Talk to your doctor if any of these become a problem for you.

Exercises that involve stretching (such as yoga) can help with your balance and strength. Meditation can help with relaxation and also helps to reduce anxiety and stress.

Does having MS affect the likelihood of having a miscarriage?

A miscarriage can happen in any pregnancy and are much more common than most people realize.¹³

Having MS does not affect your chance of having a miscarriage.⁶ However, you should be cautious with some MS treatments and how they could potentially affect the baby.

REMINDER

As a condition, MS doesn't seem to be linked with any problems with pregnancy, such as miscarriage, ectopic pregnancy, premature births, still births or birth defects.⁶



SUGGESTIONS

- Connect with MS support groups and other pre-birth ('prenatal') groups that may expand your support network.



If your partner is pregnant

What support can I provide to my partner during pregnancy?

Having MS does not have to stop you from being supportive and sharing your partner's pregnancy experience with them.



Join your partner on their pre-birth ('prenatal') appointments and scans. As well as being supportive, you will also benefit from knowing this information.



Make decisions around the pregnancy and birth as a team.



Have a healthy pregnancy together. By eating well, doing physical activity, and stopping smoking you are supporting your partner and baby. A healthy lifestyle can also help with improving MS symptoms.



Be patient and understanding of the changes your partner is experiencing. This can also help with managing your emotions about the pregnancy and new arrival; it is perfectly normal for you both to feel a range of emotions.



Share the domestic jobs where possible, such as cooking and cleaning.

Labour and delivery

If you are giving birth

Will labour and delivery be normal?

MS does not usually have an impact on labour, but this can depend on which nerves and muscles are affected.⁴

If you cannot feel contractions, you might need a bit of extra support during birth. Your obstetrician may need to use assistance to help deliver the baby, or you may need a caesarean section (also called a 'C-section'). Your doctor will discuss what your delivery options are based on your particular MS symptoms.

Can I have pain relief during labour?

Depending on your own MS activity and symptoms, most types of pain relief can be used during labour if needed. This includes pain relievers and methods to remove sensation known as anesthesia.⁴

An epidural, which is a type of anesthesia commonly used in childbirth, can be used in mothers with MS.⁴ They do not increase the chances of a relapse or affect your health once your baby is born.¹⁴ It is an individual choice as to whether or not to have an epidural, though it is recommended in certain cases.⁴

THINGS TO CONSIDER

Like anyone else having a baby, you can still make choices about your labour and delivery.



Is a caesarean section a safe option?

A caesarean section does not have any impact on the course of MS.¹⁵

Having a caesarean section is an individual choice that you and your doctor should discuss. However, for certain births, a caesarean section may be needed rather than a natural delivery for the safety of the child and/or mother.

THINGS TO CONSIDER

- Create a birth plan with support from your doctor
- Exercise to increase your strength and endurance
- Make plans for when the baby comes



If your partner is giving birth

What support can I provide to my partner during labour and delivery?

Having MS should not stop you from getting involved and sharing the birth experience with your partner.



There is no typical birth experience, and labour may happen suddenly. However, having a birth plan can be helpful, and you can support your partner by creating one together.



Attending birthing classes together can show you the ways that you can provide physical support during the birth; adapt these if necessary, based on your mobility.



During the birth, try to offer your partner emotional support when you can. Encouragement is helpful and often appreciated.



You may also be able to cut the umbilical cord, which can be a great bonding experience for you and your new baby.

After delivery

If you have given birth

Will my MS change after giving birth?

Some women may experience a change in the rate of MS relapses after giving birth. However, you may not experience any changes.

Research in women with MS who have given birth has shown a general pattern:

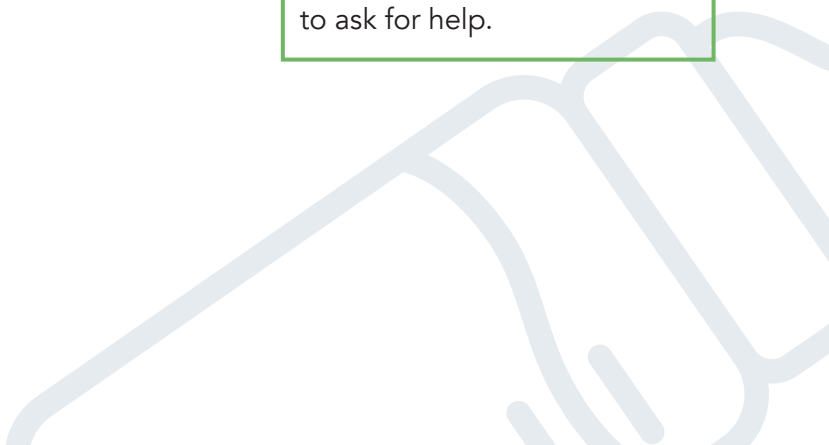
- In the first 3 months after birth, MS relapse rate may rise up to 2 times the pre-pregnancy levels.⁷ This is thought to be related to changes in hormone levels.
- Within 1 year, MS relapse rate is similar to pre-pregnancy levels for most women.⁷

You should have good control of your MS before pregnancy to reduce the chance of any major changes in your symptoms after you give birth.

REMINDER

There are no specifics on when to return to MS treatment. This will depend on whether you choose, treatment again.

All new mothers, whether they have MS or not, need to take good care of themselves to rebuild strength. Try to get plenty of rest and good nutrition, and don't be afraid to ask for help.



Can I breastfeed my child?

How you feed your new baby, whether breastfeeding or formula milk, is up to you.

However, you should make the decision with your doctor based on your personal situation, MS symptoms, and whether you need to restart treatment soon after giving birth. There is some evidence suggesting that mothers with MS who exclusively breastfeed have a lower risk of relapse in the 6 months following giving birth.¹⁶

If I stopped my MS treatment, when do I restart?

There is no specific timeline for returning to your MS treatment. However, it is important to consider that treatment is beneficial to delaying the progression of your MS.

Some women choose to, or need to, restart their MS treatment immediately and others remain off it while they breastfeed.

You can discuss your choice with your doctor.

Who should I tell about the changes in my treatment?

In some cases, not all of the people involved in your care will know of changes to your treatment. To help with this, it is useful to bring information with you to all your appointments. For example, about your epidural if you have had one.

THINGS TO CONSIDER

- Decide whether to breastfeed, formula feed or combination feed, and remember that it's your decision
- Keep talking to your healthcare team and get your support team involved
- Learn about your new baby and their care





If your partner has given birth

What do I need to consider after delivery?

Some partners with MS may worry about the level of support they can provide when the baby arrives or having to cope if they have an MS relapse in the early days. It may be helpful to consider the following:



Try not to worry and put too much pressure on yourself. It is normal to have times when you feel fatigued and may not be able to help as much.



Ask others for help if possible. Do not feel you have to take on everything. Be realistic in what you can manage and ask for help when you feel you need it.



Remember, no matter how you spend time with your family, the most important thing is that you're sharing care and love.



Keep talking and listening to your partner so you can support each other, and talk to others if you need to.

Life with a new baby

What should I have planned for after the birth?

It's a good idea to start planning early for the few weeks and months after the birth, as organizing things can be difficult once the new baby arrives.

If you experience fatigue, it may be worth making changes to help you move around your home more easily. Work with your partner to make adaptations that suit you both.

There are also many parenthood books and other helpful resources that can help you and your partner plan.

How will I feel when the baby arrives?

The time after delivery is known as the 'postpartum' or 'postnatal' period. Like all new parents you may experience physical and/or emotional changes.

Some new parents can feel down, tearful or anxious after

the birth of a child. This is common in the first 2 weeks following the birth.¹⁷

If this lasts longer for you, it may be a sign of depression. If you think you are experiencing depression, it is important you seek help as soon as possible so you can get the right support.

What are my employment rights for paternity/maternity leave and time off of work?

The Canadian government Employment Insurance program provides financial assistance in the form of:

- **MATERNITY BENEFITS**
For people who are away from work because they're pregnant or have recently given birth. These cannot be shared between parents, but the person receiving maternity benefit may also be eligible for parental benefits.
- **PARENTAL BENEFITS**
For people who are away from work to care for their newborn

or newly adopted child. These can be either standard or extended, depending on the number of weeks and the weekly amount you'll receive.

If you're sharing benefits, you must both choose the same option and submit separate applications. You

can receive these benefits at the same time or one after the other. Either way, once you start receiving parental benefits you cannot change options.¹⁸

For a full benefit overview, contact a Service Canada agent or visit the Government of Canada website.

THINGS TO CONSIDER

All parents need help from time to time. Talk to the people who can support you. Explain what kind of help you might need:



Shopping



Cooking



Cleaning



Caring for other children



Filling the freezer with food



Watching the baby if you or your partner need to rest

THINGS TO CONSIDER



Talk to other parents living with MS. Hearing their experiences first-hand can be very insightful and helpful to your journey.

Raising a family

Is there any advice for people with MS who are raising a family?

Early days of family life with a new child can bring challenges, no matter who you are. Here are some tips for life as a new parent with MS, and beyond:¹⁹



Try to focus on your health and bonding with your new baby or child. This will help develop the relationship between the both of you.



Don't be afraid or embarrassed to ask for help. Let the people around you support you with daily activities when they offer.



Don't compare yourself with other parents. In a world filled with perfect images, it can be easy to feel like you are not doing enough. This is not the case – try to focus on your own family, life, and needs.



Adapt family time around your symptoms. You may find spending time with the family exhausting at times. There are many ways to have fun without needing to run around or travel about. In fact, you may find the simplest bonding times are the most rewarding, such as doing puzzles.



If you already have children, **you may want to consider talking with them about your MS.** You may naturally want to protect them from any worries about your condition. Children are often tougher than we think, and they may surprise you with how supportive they are.

Resources and support

Who are the experts that can support me?

Your partner, friends, and family can provide key support when starting and growing your family. If you need further support, remember that healthcare professionals are there to help. You may not have access to all of them, but this section can act as a guide to who can help you and how.

You can add in their contact details in the spaces provided to keep them all in one handy place:

General practitioner, MS nurse and neurologist

Advice on contraception and on how best to manage MS

Midwife and obstetrician

Support before and during labour and delivery

Gynecologist

Support during the preparation for pregnancy and help with fertility and female sexual problems

Urologist

Help with urinary symptoms and male sexual problems

Pharmacist

Medicine dispensing and advice about medicines and pregnancy/breastfeeding

Physiotherapist

Exercise programs tailored to pregnancy and MS, designed to improve or maintain strength, mobility, balance, and coordination

Occupational therapist

Advice on modifying activities to better suit pregnancy and MS, and on adaptations for the home or workplace

Psychologist

Support during preparation for parenthood, during pregnancy, and following birth

Sex therapist

Advice on MS-related and other sexual problems

References

1. Genetics Home Reference. Multiple Sclerosis. Available at: <https://ghr.nlm.nih.gov/condition/multiple-sclerosis#inheritance>. Accessed December 2019.
2. Compston A and Coles A. Multiple sclerosis. *Lancet*. 2002;359(9313):1221–1231.
3. Government of New Brunswick. Is Fostering Right For You? Available at: http://www2.gnb.ca/content/gnb/en/departments/social_development/foster_care/fostering.html. Accessed May 2020.
4. Dobson R, et al. UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines. *Pract Neurol*. 2019;19(2):10614.
5. Amato MP and Portaccio E. Fertility, pregnancy and childbirth in patients with multiple sclerosis: impact of disease-modifying drugs. *CNS Drugs*. 2015;29(3):207220.
6. Airas L and Kaaja R. Pregnancy and multiple sclerosis. *Obstet Med*. 2012;5(3):94–97.
7. Hughes SE, et al. Predictors and dynamics of postpartum relapses in women with multiple sclerosis. *Mult Scler*. 2014;20(6):739–746.
8. Pardo G, Jones DE. The sequence of disease-modifying therapies in relapsing multiple sclerosis: safety and immunologic considerations. *J Neurol*. 2017;264(12):2351–2374.
9. Bearak J, et al. Global, regional, and subregional trends in unintended pregnancy and its outcomes from 1990 to 2014: estimates from a Bayesian hierarchical model. *Lancet Glob Health*. 2018;6:e380–e389.
10. Canada.com. MS and Pregnancy. Available at: <http://bodyandhealth.canada.com/healthfeature/gethealthfeature/ms-and-pregnancy>. Accessed May 2020.
11. Lee M and O'Brien PJ. Pregnancy and multiple sclerosis. *J Neurol Neurosurg Psychiatry*. 2008;79:1308–1311.
12. Confavreux C, et al. Rate of pregnancy-related relapse in multiple sclerosis. *N Eng J Med*. 1998;339:285–291.
13. HealthLink BC. Miscarriage. Available at: <http://healthlinkbc.ca/health-topics/hw44090>. Accessed May 2020.
14. Bettencourt M, et al. Epidural anaesthesia for caesarian in a multiple sclerosis patient. *Eur J Anaesthesiol*. 2014;31:181.
15. MS Society. Pregnancy. Q&A. Available at: <http://mssociety.ca/managing-ms/womens-health/pregnancy>. Accessed May 2020.
16. Hellwig K, Rockhoff M, Herbstritt S, et al. Exclusive breastfeeding and the effect on postpartum multiple sclerosis relapses. *JAMA Neurol*. 2015;72(10):1132–1138.
17. HealthLink BC. Baby Blues. Available at: <http://healthlinkbc.ca/health-topics/tn7417>. Accessed May 2020.
18. Government of Canada. EI maternity and parental benefits: what these benefits offer. Available at: <https://www.canada.ca/en/services/benefits/ei/ei-maternity-parental.html>. Accessed December 2019.
19. MS Trust. Juggling MS and family life. Available at: www.ms-trust.org.uk/news/views-and-comments/juggling-ms-and-family-life-five-top-tips. Accessed July 2019.