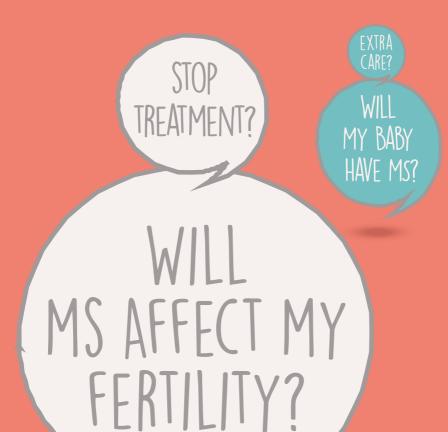
I am trying for a baby



Family planning for people with MS booklet series

INTRODUCTION TO THE 'FAMILY PLANNING FOR PEOPLE WITH MS' SERIES

This is the first of three booklets that discuss important issues for people with multiple sclerosis (MS) who want to have a baby. The decision to have a child is huge for anyone and, as a person with MS, we know you have a lot of other things to think about. These booklets share up-to-date information on family planning and MS. They have been written by a group of doctors with expertise in fertility, MS and family planning, pregnancy, and women who became mothers after their MS diagnosis.

We hope these booklets will help you to make the **best decisions possible** during your family planning experience.

Meet the authors

- **Gráinne Rouleau** is a mum with MS. She gave birth to her daughter 3 years ago, 9 years after her MS diagnosis.
- **Julia Hubinger** is a mum with MS. She gave birth to her first child 9 years ago, 1 year after her diagnosis. She now has three children.
- **Professor Eleonora Cocco** is the Director of the Multiple Sclerosis Center of Cagliari, ATS Sardegna/University of Cagliari, Italy.
- **Professor Michael Grynberg** is the Head of the Department of Reproductive Medicine and Fertility Preservation at University Hospital Antoine Béclère in Clamart, France.
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DECIDING TO START A FAMILY

Having MS does not mean that you cannot start a family,¹

but you may have many questions about how your MS might affect the chance of you having a healthy baby, and how pregnancy

could affect your MS.^{2,3} This booklet will answer some of your questions about trying to have a baby while managing your MS. You can use it as a guide to help you to **talk to people** about planning to have a baby.

What you need to know

- You can have a healthy baby, even if you have MS.⁴⁻⁷
- Your neurologist and MS nurse can help you decide on a treatment plan for your MS while you are planning to have a baby.
- Talk to your neurologist and MS nurse as soon as you start to think about having children.
- Some women with MS might find that they have fewer relapses when they are pregnant and, in the long term, pregnancy does not seem to lead to more relapses or make relapses worse.^{4,8}

WILL MS AFFECT MY CHANCE OF HAVING A HEALTHY BABY?

If you are a woman with MS, studies have shown that your disease shouldn't affect your chance of getting pregnant.⁴ Women with MS and women without MS have similar risks of:

- miscarriage the risk is 20.9% in women with MS, compared with 20.0% in women without MS⁶
- stillbirth the risk is 0.6% in women with MS, compared with 0.7% in women without MS,⁵ or
- birth abnormalities the risk is 3.9% in women with MS, compared with 4.4% in women without MS.⁵



"It's so important that people who live with MS are able to build families and not be held back in that respect by their disease."

MS is not passed directly

from parents to children, but

children do have a potentially higher chance of getting MS if one of their close family members has the condition – 2 to 2.5% chance, compared with 0.1 to 0.3% in children without a family history of MS.^{48,9}

QUESTIONS YOU MAY HAVE ABOUT STARTING A FAMILY

Talk to your neurologist, gynaecologist or MS nurse as soon as you decide that you want to try for a baby. They will help you manage your MS symptoms while you try to get pregnant, which could take some time. They will also look at your full medical history, and are likely to recommend that you are up to date with all your vaccinations.¹⁰

Your doctor will also think about your MS medicine, if you are taking any. **There are some MS medicines that you must not take when you are pregnant.**^{8,11}

Remember! You should continue to use contraception until your doctor tells you it is safe to stop.

WILL PREGNANCY AFFECT MY MS?

How being pregnant may affect your MS can depend on your disease activity, but generally, your neurologist might recommend that you wait until your disease is **under control with treatment** before you try for a baby.^{8,9} Choosing the **right treatment plan** for you is very important.

Will I have more relapses when I'm pregnant?

Women with **mild to moderate MS** often have **fewer** MS relapses when they are pregnant, especially during the last 3 months of pregnancy.¹²⁻¹⁵

If you have **highly active MS**, pregnancy may not reduce the number of relapses you have,¹¹ but you might be able to take a medication for your MS for some time during your pregnancy or while you are trying to get pregnant.^{8,11,16}

HOW MIGHT PREGNANCY AFFECT MY DISABILITY?



"I didn't have a relapse during pregnancy."

Common pregnancy symptoms might make some of your MS symptoms feel worse,¹⁷ but this doesn't necessarily mean that your MS has gotten worse.

You can find out more in Booklet 2, 'I am pregnant'.

Will having a baby mean that I will have more MS relapses in the future?

Advances in the treatment of MS mean that for many women with MS, symptoms don't get worse after they give birth.¹⁸

If you're thinking about having more children and had relapses in your first pregnancy, this doesn't mean that you will during your next pregnancy.¹⁹ **Every pregnancy is different.**

In the long term, pregnancy shouldn't lead to more relapses,^{7,8} even if you have a relapse after giving birth.¹⁸

You can find more information in Booklets 2 and 3, 'I am pregnant' and 'I am a mother'.

LOOKING TOWARDS THE FUTURE

There are lots of things to look forward to as your child grows up, but it's important to remember that your condition may also change with time²⁰ and to think about how it might affect childcare.

- If you have a **partner**, include them in all your conversations with your medical team.
- Talk to your **family and friends** about how they might be able to help you.

Can my partner, family or friends help?

If something happened, how would it affect people around me?

Would we have enough money to provide for the baby?

Do we want more children?

"I thought MS should not be a reason not to become a mother – I won't let the MS win." – Julia "Don't be afraid of the future. Decide in the present because you never know the development of your MS. If you are ready to have a baby now, don't think of all the impairments the MS might cause. You don't know if it will really happen." – Julia



TRYING TO CONCEIVE

Plan ahead

• Where can you find help?

Family doctor, specialized doctor or gynaecologist Local health services and support groups Patient support programmes Partner, friends and family Blogs, chat groups, Instagram or YouTube channels hosted by parents with MS Local MS society, if one is available in your region Other mums with MS

> "My neurologist said, 'There's no reason you can't conceive like anyone else'." – Gráinne

"Ultimately, deciding to have a baby was the outcome of many, many conversations with my husband." – Julia

Overview of the family planning journey as a person with MS



Talk to experts, your partner and your family and friends as soon as you decide to try for a baby



Timing

When do you want to become pregnant? In the next few months? Or in the next few years? Is your disease under control with treatment?^{8,9}



Disease activity

Do you have mild to moderate MS or high disease activity?



Fertility

- MS shouldn't stop you from having a healthy baby⁴⁻⁷
- Women and men with MS might experience sexual problems (for example, loss of desire to have sex or difficulty achieving an orgasm)^{8,21}
- The chance of getting pregnant gets lower as you get older²²
- Almost 1 in 10 women with MS have difficulty getting or staying pregnant.^{4,8} This figure is similar for women without MS across the world
- A fertility expert can support you if you have problems getting pregnant



Fertility treatments might

help you to get pregnant, but they can be expensive and don't always work. Some fertility treatments for women might increase your risk of an MS relapse^{8,11,23,24}



Treatment

- Work with your neurologist to choose the right plan for you
- Your neurologist may ask you to do one or more of the following:
 - Continue taking your current MS medication during pregnancy.
 - **Stop** your current MS medicine.
 - Switch to an MS medication that can be used during pregnancy
- Use contraception until your doctor tells you it's safe to stop. Some medicine stay in your body for a while after you stop taking them. This means you may have to continue to use contraception for some time after stopping your MS therapy.²⁵ Your neurologist may also recommend that you use more than one type of contraceptive¹¹



Other things to consider

- If you want to breastfeed, talk to your doctor or MS nurse
- Having more children. Every pregnancy is different¹⁹



WHAT ARE MY MS TREATMENT OPTIONS AS A WOMAN WANTING TO GET PREGNANT?

If you're taking an MS medication, your neurologist will discuss any possible risks to your baby and help you decide if you should continue with your treatment to help prevent relapses.

If you have mild to moderate relapsing MS, your neurologist might say that you can **stop** taking your MS medication while you try to get pregnant, and continue to monitor your MS.⁸

Some MS medicines can be taken while you try to get pregnant.^{8,11,16} You may need to **change** your MS medication if you're taking one that cannot be taken during pregnancy.

 Some MS medicines can take weeks or months to leave your body after you stop taking them. This is called a washout period. You should avoid trying to get pregnant until the medication has left your body, and use contraception for as long as your neurologist recommends.²⁵

"I talked to my neurologist when I decided I wanted to have a baby. I stopped taking my MS medication. I got pregnant very quickly, but I agreed with my neurologists to have an MRI in 3 months if I hadn't become pregnant."



If you are thinking about having a baby in a few years' time, your doctor may consider prescribing MS medicines that you can take periodically while helping to manage your disease, allowing you **to try to get pregnant** when you stop taking it.¹¹ You can find more information in Booklet 2, 'I am pregnant'.

WHAT ARE MY MS TREATMENT OPTIONS AS A MAN WANTING TO BECOME A FATHER?

Most MS treatment can be taken by men who want children. However, there are some that you shouldn't take if you are trying to have a baby with your partner.¹¹ If this applies to a medicine you are taking, you can discuss with your Neurologist to:

- **stop** taking it for a while and restart it after your partner is pregnant
- **change** to an MS medicine that can be taken while you try to get your partner pregnant, or
- take a medicine that can control highly active MS for a few years (even after you stop taking it).

Remember! Talk to your neurologist before stopping or changing your MS treatment.



WHAT IF I STRUGGLE TO GET PREGNANT?

There are **lots of reasons** why it may take some time to get pregnant. One of the main things that can affect your ability to get pregnant is your **age**, as your chance of getting pregnant reduces as you get older.²⁶

WHAT CAN I DO TO INCREASE MY CHANCE OF GETTING PREGNANT?

What can I do to help me get pregnant?^{9,27}

- Maintain a healthy weight and eat healthy foods
- Avoid stress
- Don't smoke
- Don't drink too much caffeine or alcohol
- Get enough sleep
- Try for a baby when you are most fertile. This is when the egg is released during your menstrual cycle (ovulation). Ovulation prediction kits and fertility tracker apps may be helpful
- Your doctor might recommend that you talk to a fertility expert and think about options that might be available to help you get pregnant (fertility treatments)



Calendar^{28,29} $\square 4$

The calendar below shows which days in your menstrual cycle are your most fertile:

Menstrual period, most fertile days, \bigcirc = ovulation

When to talk to a doctor about fertility²⁶

Women

- If you are **under 35 years old** and have been trying to get pregnant for more than a year
- If you are **35 years old or older** and have been trying to get pregnant for more than 6 months
- If you have had problems getting or staying pregnant in the past

Men

- If you have been trying to get your partner pregnant for **more than a year**
- If you have **had problems** getting a partner pregnant in the past

Your doctor may refer you to a fertility specialist if necessary.

WILL A DELAY IN BECOMING PREGNANT AFFECT MY MS?



"That's a long time to be off medication – the months before conception, and then 9 months of pregnancy. I just knew it was something that had to happen."

If you stop taking your MS medication while you try to get pregnant, your doctor will continue to check your MS. They will tell you if they think you need to start taking your treatment again at any time.

If you continue to take a medication for your MS while trying to get pregnant, your doctor will continue to check on you as normal until you get pregnant.



Call your doctor if you notice a change in your MS symptoms while you are trying to get pregnant.



What fertility treatments could help me conceive?

MS shouldn't affect a woman's ability to conceive.⁴ However, men and women with MS may experience some sexual problems²¹ and about 1 in 10 women with MS has difficulty getting or staying pregnant.⁴ This figure is similar for women without MS across the world. If you are (or your partner is) having difficulty conceiving, you can talk to a **fertility expert**.

It's important to remember that fertility treatment can be a long, emotional, stressful journey that can cost a lot of money and **may not always work**.

Fertility treatment	What does it mean?	When would this be used?	What is the chance it will help?
Intrauterine insemination (artificial insemination)	Sperm are inserted into the woman's womb	If men have low sperm count or reduced sperm movement, or if a sperm donor is used	A 1 in 5 (20%) chance of success ^{30,31}
In vitro fertilization (IVF) ³²	Egg cells are taken from the woman and sperm from the man. They are mixed outside of the body and then the resulting embryo is put into the woman's womb	If women or men have fertility problems (for example, obstructed fallopian tube, endometriosis, low sperm count)	Up to 31% chance of success ⁸
Intracytoplasmic sperm injection	This is a type of in vitro fertilization in which a single sperm is placed directly into a woman's egg cell	If men have fertility problems (for example, very low sperm count)	Similar success to in vitro fertilization ³³

Some women may want to use other techniques to help them have a baby, for example, by freezing some of their egg cells to use in the future. If you have any questions about this, you can talk to a **fertility expert**.

Œ

ASK A FERTILITY EXPERT!

In this section, a fertility expert answers some common questions about fertility treatments.

QUESTION: When should I think about starting fertility treatment?

ANSWER: If fertility treatment has been recommended, you should think about starting it when your **disease activity is stable**.

QUESTION: If I need to use fertility treatments to help me get pregnant, will this affect my MS?

ANSWER: A small amount of information shows that some fertility treatments might increase relapses in women with MS.^{8,11,23,24} Your fertility doctor should be aware of this, and it **may not affect the treatment** used to help you become pregnant.

QUESTION: Will fertility treatment affect treatment of my MS?

ANSWER: Your fertility specialist will discuss this with you, but it is **unlikely that treatment for your MS will change**.

"You don't have to be a fully healthy mum or dad. Children need **love**, **understanding** and **respect**; they can cope with illness, but not without love." – Julia

At the end of this booklet we have included a blank page for you to write down any questions you may have for your neurologist.

MORE INFORMATION

Where can I get more information?

- Your neurologist and gynaecologist
- Your family doctor
- Your MS treatment patient support programme (if one is available near where you live)
- Your local MS society's website (if a local MS society is available near where you live)
- Blogs, Instagram, YouTube channels and social-media chat rooms hosted by other mums with MS

SEE THE OTHER BOOKLETS IN THE SERIES FOR MORE INFORMATION

- Booklet 2: I am pregnant
- Booklet 3: I am a mother

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Keep this booklet with you. If you have any questions, write them down here so that you remember to ask them at your next appointment.



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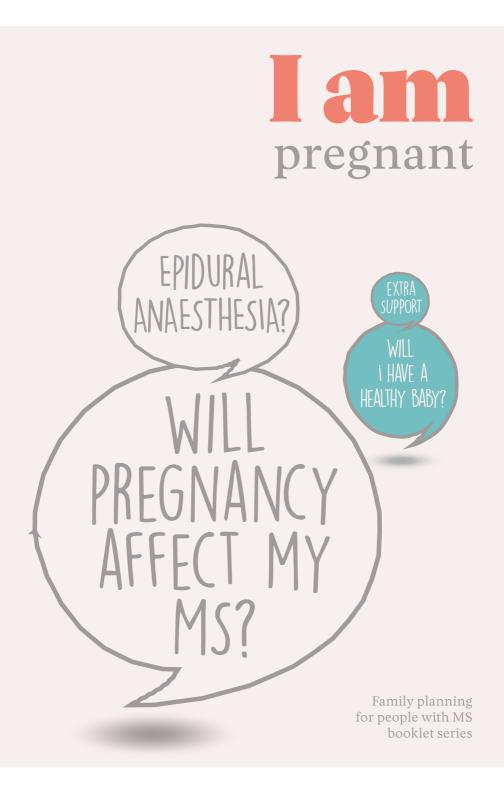
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Merck is proud to support women living with multiple sclerosis (MS), who don't let their condition stop them from living the life they choose, which includes having children if they want to. By providing supporting information on MS, pregnancy, childbirth and lactation, Merck hopes to encourage women to have open discussions on this important subject.

At Merck, we are committed to improving MS from the inside out. #MSInsideOut

With the friendly support of Merck



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BOOKLET 2

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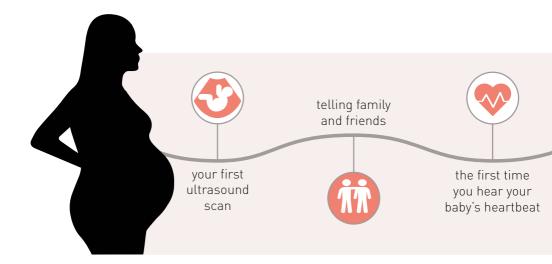
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CONGRATULATIONS! YOU'RE PREGNANT!

This booklet will guide you through what to expect during your pregnancy as a woman with MS, and how to plan for the birth of your child.

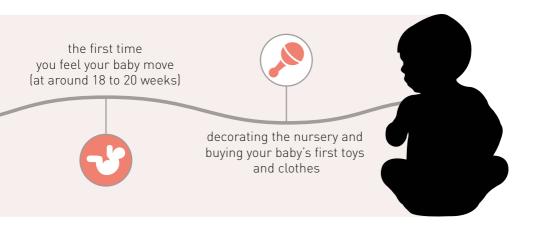
THINGS YOU CAN LOOK FORWARD TO OVER THE NEXT 9 MONTHS

Your MS shouldn't stop you from having a healthy pregnancy and baby, and it's **likely that your care will be the same** as it would if you didn't have MS. There are many things to look forward to throughout your pregnancy, including:





"When I found out I was pregnant I was worried that my baby might not be healthy. I discussed my worries with my MS nurse who reassured me that I should be able to give birth to a healthy baby."



Having MS shouldn't affect your baby's health. Babies born to mothers with MS are **just as likely to develop normally** as those born to women who don't have MS.¹

"When I found out I was pregnant I was worried my baby might be harmed because of the MS medication I was taking." – Julia

If you are taking a medication for MS, tell your neurologist as soon as you know you are pregnant. They will discuss any risks to your baby and help you decide if you need to continue treatment.



Data on almost 900 pregnancies have shown that, for some women, pregnancy may protect against MS relapses. This means you might find that your MS becomes more stable during your pregnancy, especially during your third trimester – Weeks 28 to 40 of your pregnancy.²

WHO SHOULD I TELL THAT I'M PREGNANT?

You should discuss your pregnancy with your neurologist and MS nurse as soon as possible to help you manage your MS during your pregnancy and after your baby is born. You should also tell your doctor and the medical team looking after you during your pregnancy that you have MS. This team isn't the same for everyone, but often includes an obstetrician or gynaecologist, midwives and nurses. It's likely that you will receive the same care as women who don't have MS.

It might be helpful to get a **letter from your neurologist** to put in your maternity notes to tell the healthcare professionals looking after you during your pregnancy (for example, gynaecologist, midwife or obstetrician) about your MS. The letter could include advice on anaesthesia and managing pain during labour.



"I wish I'd told my neurologist that I wanted to breastfeed..."

Remember to tell your neurologist early on if you would like to breastfeed. If you need to start taking a medication for MS immediately after your baby is born, they may be able to prescribe one that can be taken while you are breastfeeding.

WHAT TO EXPECT

Pregnancy can be an exciting experience, but it can also put your body under more stress than usual. There are a number of physical symptoms that you might experience at different stages of your pregnancy.³⁻⁶ **These can be completely normal** and can be the same for women with or without MS. If you're worried about any of these symptoms, speak with your doctor, who can help you find ways to manage them.

SYMPTOMS YOU MIGHT EXPERIENCE

FIRST TRIMESTER

(Weeks 0 to 12)



SECOND TRIMESTER

(Weeks 13 to 27)



THIRD TRIMESTER

(Weeks 28 to 40)





"Pregnancy yoga and aqua gymnastics helped me a lot during my pregnancies."

"I kept active throughout my pregnancy – I kept hiking until my waterproof clothes didn't fit anymore. Walking helped me relax in the build-up to labour." – Gráinne

URINARY INFECTIONS

Urinary (or urinary tract) infections can be common during pregnancy and **may be more likely** in women with MS.⁷⁻⁹ They are easy to treat, but if left untreated they can make your MS symptoms temporarily worse or cause a relapse.^{7,10} There is also a chance that they could bring on early labour.^{11,12}



Look out for symptoms of urinary infections. These include tiredness, back or stomach pain, passing urine more often, pain or burning when urinating, only managing to pass small amounts of urine at a time, or cloudy or strong-smelling urine.¹³

PREGNANCY AND MS

HOW WILL PREGNANCY AFFECT MY MS?

Pregnancy won't make your MS worse. It might even slow down your MS progression. Studies have shown that the chance of women with MS having a relapse lessens during pregnancy, particularly during the third trimester.^{2,14-17}

RELAPSES

WILL I RELAPSE DURING PREGNANCY?

If you have mild or moderate MS, it's **unlikely that you will relapse** during pregnancy. In fact, studies have shown the likelihood of having a relapse can go down during pregnancy, especially during the last 3 months.^{2,14–17}

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"I didn't relapse during pregnancy."



If you have very active MS with a lot of relapses, you could be more likely to have a relapse while you are pregnant. To help reduce your chance of a relapse, your neurologist may consider a medicine for MS that you can take for short periods to help manage your disease, allowing you to try to get pregnant when you stop taking it. They may also suggest a medicine for MS that you can take while you are pregnant.^{10,18–20} Your neurologist can talk you through the best action to take if you have a relapse while you are pregnant.

If this is not your first pregnancy and you had relapses when you were pregnant before, this doesn't mean you will have relapses during this pregnancy.²¹ **Every pregnancy is different.**



Some symptoms of pregnancy are similar to symptoms of an MS relapse, for example, tiredness, weakness or stiffness, constipation, needing to urinate often, balance problems, back pain and changes in vision.²² If you are concerned or notice that your MS symptoms are getting worse, don't be afraid to call your doctor.

WILL I HAVE A RELAPSE AFTER MY BABY IS BORN?

Around 1 in 10 women may have a relapse within the first 3 months after their baby is born. You may be less likely to have a relapse after giving birth if, throughout the 2 years before getting pregnant, you were taking a medicine for MS or your MS was stable.² How your baby is delivered (whether you have a vaginal birth or a Caesarean section [C-section]) will depend on your labour and won't affect your risk of having a relapse after the birth.²³

If you had mild MS before and during your pregnancy, your neurologist will probably monitor you closely and advise you to start taking a medicine for MS again if you need to.²⁴ If you had very active MS before your pregnancy, your neurologist may suggest that you start taking a medicine for your MS again as soon as possible after giving birth.



"I was concerned about relapsing after having the baby. I wondered how soon a relapse would happen and how bad it would be or if I would need extra help. But I knew that worrying about it wouldn't stop a relapse, so I tried not to let it get me down."



After your baby is born, you may feel like your MS symptoms are worse. You may feel very tired, low or depressed, or have problems passing urine.¹⁴ If you have any concerns, please speak with your doctor.

MS TREATMENT

SHOULD I STOP TAKING MY MEDICINE FOR MS NOW THAT I'M PREGNANT?

There are some medicines for MS that you shouldn't take while you are pregnant.²⁵⁻²⁷ However, if your neurologist thinks that it would be better for you to take a medicine for MS while you are pregnant, they will explain your options to you.



WHAT IF I HAVE A RELAPSE WHILE I'M PREGNANT?

If you have a relapse and your neurologist thinks you need an MRI scan (a scan of your body that uses magnetic fields), you can have one while you are pregnant.^{10,14,19} If you have a severe relapse, which your neurologist thinks needs treating, there are steroids that you can take while you are pregnant.³⁷ If you have a very severe relapse and steroids don't work, your neurologist might offer you a treatment called plasma exchange to 'clean' your blood.^{10,19}

HOSPITAL BAG CHECKLIST

Think about the things that help you manage your MS at home that you might like to take to the hospital with you. At the end of this booklet we have included a pull-out list with some examples of what to include in your hospital bag, and space for you to add your own ideas.



giving Birth

AM I IN LABOUR?

If your MS has caused back problems or numbness from your waist down, you may not realize you have gone into labour. **Look out for other signs** such as increased stomach tightness, feeling or being sick, flushing or back pain.¹⁰

HOW WILL MS AFFECT MY LABOUR?

Having MS doesn't mean that you are more likely to have a difficult birth, but it is recommended that you give birth in hospital rather than at home.³⁸

It might be helpful to get a **letter from your neurologist** to put in your maternity notes, to tell the medical team looking after you during your pregnancy about your MS. The letter may include advice on anaesthesia and managing your labour, such as:

- you can have an epidural anaesthesia, and
- a long labour (28 to 36 hours) may not be advised for some women with MS.

WHAT PAIN RELIEF CAN I TAKE DURING LABOUR?³⁹

Depending on how your MS affects you, you may consider a water birth, TENS (small, safe electrical currents applied to your lower back), acupuncture or hypnobirthing (techniques to help you feel calm and in control during labour). **You can have the usual pain relief** while you are in labour, including an epidural.¹⁰ Pain relief and an epidural can help during labour if your MS causes muscle tightness.¹⁰ Speak to your neurologist and the medical team looking after you during your pregnancy for more information.

Gas and air

What is it?

A gas that you breathe in through a mouthpiece during contractions, to help reduce pain

Side effects

You may feel sick or light headed

Risks to baby

Pethidine or diamorphine injection

What is it?

An injection in your thigh or buttock to relieve some pain and help you relax

Side effects

You may feel sleepy or sick and your breathing may slow

Risks to baby

Your baby may be slow to breathe and drowsy, and may find it hard to feed at first

Patient-controlled intravenous analgesia (PCA)

What is it?

Pain relief given into your vein for a faster effect. You control when you have the pain relief by pressing a button as each contraction starts

Side effects

You may feel sleepy or sick and your breathing or heart rate may slow

You may be more likely to need an assisted birth (with help from forceps or a 'suction cup')

Risks to baby

Your baby may be slow to breathe at first

Epidural or combined spinal epidural (CSE)

What is it?

A type of local anaesthetic and pain relief that is given through a small tube in your back that numbs the nerves carrying pain impulses from the birth canal to the brain

Side effects

You may have low blood pressure

You may find it difficult to pass urine, in which case you may be offered a catheter (a tube into your bladder to help you pass urine)

You may get a bad headache or have an increase in body temperature

You may get temporary nerve damage (very rarely is the nerve damage permanent or severe)

You may be more likely to need an assisted birth

Risks to baby

If you have low blood pressure, your baby's heart rate may be affected at first

my birth plan

There are many things to think about when preparing for your baby's birth. At the end of this booklet we have included a pull-out page with a birth plan for you to fill in. Some things to think about when writing your birth plan are listed below.

Labour and birth

- Does your MS mean you have limited mobility and flexibility?
 Consider how the coping tools you use at home could help you in the delivery room.
- You might want to discuss with the medical team looking after you during pregnancy how your MS symptoms might affect your labour.

The team might refer you to a physiotherapist while you are pregnant, to help you get ready for labour.¹⁰

Pain relief

• Think about what sort of pain relief you would prefer.

Third stage (delivery of your placenta)

• Before you go into labour, you should discuss with your medical team how your placenta will be delivered.

You may be offered an assisted delivery, but you may be able to choose to deliver it naturally.

Unexpected situations (for example, assisted births)

- You may find that your labour takes longer because of your MS and that you get tired more easily, especially if you have MS fatigue.²²
- You might need some help delivering your baby, especially if you have limited mobility. The medical team looking after you may use instruments (for example, forceps or a 'suction cup') to help deliver your baby.^{22,24,38}
- If there are concerns about your baby's health, you may need to have a Caesarean section to deliver your baby quickly.^{22,24,38,40}

Remember, while it's important to think about how you would like your labour to be, it might not go to plan. The doctors and midwives looking after you will always try their best to do what you want, but their priority is to deliver your baby safely.

At the end of this booklet we have included a blank page for you to write down any questions you may have for your neurologist. "My husband was with me during my three deliveries." – Julia "The midwives were a great support and helped me have a natural birth!" – Julia



"Medication! I had an epidural, which helped a lot!" – Gráinne

"Given my diagnosis of MS, words cannot describe how amazing it felt to give birth – my 'ill body' had done something wonderful!" – Julia

MORE INFORMATION

Where can I get more information?

- Your neurologist and gynaecologist
- Your family doctor
- Your MS treatment patient support programme (if one is available near where you live)
- Your local MS society's website (if a local MS society is available near where you live)
- Blogs, Instagram, YouTube channels and social-media chat rooms hosted by other mums with MS

SEE THE OTHER BOOKLETS IN THE SERIES FOR MORE INFORMATION

- Booklet 1: I am trying for a baby
- Booklet 3: I am a mother

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Hospital bag checklist

Think about the things that help you manage with your MS at home and that you might like to take to the hospital with you.

Your hospital paperwork for bot including a note from your neur looking after you during the birt not affect what pain relief you co not advised for women with MS	ologi :h, ex	st to the medical team plaining that your MS does
Your birth plan		Disposable underwear
Any medicines you take		Nursing bra (if you would like to breastfeed)
Enough loose and comfortable clothes for a few days' stay in hospital		Snacks and drinks* Toiletries
Maternity pads		A book/magazine

HOSPITAL BAG CHECKLIST

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continued from previous page

YOUR BABY	YOUR PARTNER
 Vests Baby grows and sleepsuits Hats, socks and booties Going-home outfit and blanket Nappies Wipes Car seat 	 A copy of the birth plan Any medicines you take Snacks and drinks* Money Camera (check to see if they are allowed to take photos and videos) Phone Toiletries
	Image: Second

E MY BIRTH PLAN	
Due date	
Birthing partner's name and contact details	
Labour and birth	
Pain relief	
continued on new	

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MY BIRTH PLAN

Third stage (how I would like my placenta to be delivered)

Unexpected situations (for example, assisted births)

Other things that are important to me

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Keep this booklet with you. If you have any questions, write them down here so that you remember to ask them at your next appointment.



Disclaimer

This booklet is intended to be used as a general guide. The information in it should not replace medical advice, independent judgement or proper assessment by a doctor who has considered your particular circumstances and needs. This booklet reflects information that was available at the time it was prepared, and you should consider it alongside any information that has recently become available. Merck does not accept any liability to you as a result of using the information in this booklet. Always seek the advice of your treating Healthcare Professional if you have any questions regarding your individual treatment plan.

Further information is available on request or may be found in the Package Insert. Merck (Pty) Ltd. Reg. No.:1970/004059/07. 1 Friesland Drive, Longmeadow Business Estate South, Modderfontein, South Africa, 1645. Tel: +27 (0) 11 372 5000 / Fax: +27 (0) 11 372 5252. Report adverse events to drug.safety.southeastafrica@merckgroup.com or +27 (0) 11 608 2588 (fax). ZA_NONNI_00092|March 2025.

Merck is proud to support women living with multiple sclerosis (MS), who don't let their condition stop them from living the life they choose, which includes having children if they want to. By providing supporting information on MS, pregnancy, childbirth and lactation, Merck hopes to encourage women to have open discussions on this important subject.

At Merck, we are committed to improving MS from the inside out. #MSInsideOut

With the friendly support of Merck

a mother



HOWD

CARE

supporting My pArtner

BABY?

Family planning for people with MS booklet series

INTRODUCTION TO THE 'FAMILY PLANNING FOR PEOPLE WITH MS' SERIES

This is the last of three booklets that discuss important issues for people with multiple sclerosis (MS) who want to have a baby. The decision to have a child is huge for anyone and, as a person with MS, we know you have a lot of other things to think about. These booklets share up-to-date information on family planning and MS. They have been written by a group of doctors with expertise in fertility, MS and family planning, pregnancy, and women who became mothers after their MS diagnosis.

We hope these booklets will help you to make the **best decisions possible** during your family planning experience.

Meet the authors

- **Gráinne Rouleau** is a mum with MS. She gave birth to her daughter 3 years ago, 9 years after her MS diagnosis.
- **Julia Hubinger** is a mum with MS. She gave birth to her first child 9 years ago, 1 year after her diagnosis. She now has three children.
- **Professor Eleonora Cocco** is the Director of the Multiple Sclerosis Center of Cagliari, ATS Sardegna/University of Cagliari, Italy.
- **Professor Michael Grynberg** is the Head of the Department of Reproductive Medicine and Fertility Preservation at University Hospital Antoine Béclère in Clamart, France.
- **Professor Kerstin Hellwig** is a senior consultant and MS specialist at St Josef and St Elisabeth Hospital Katholisches Klinikum in Bochum, Germany.
- **Professor Celia Oreja-Guevara** is the Vice Chair of Neurology at Hospital Clínico San Carlos in Madrid, Spain.

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BECOMING A MOTHER

Your baby is finally here! Congratulations! Whether you're a first-time mother or have other children, you may have questions about managing your MS while tackling motherhood.¹ This booklet will guide you through taking care of your baby and yourself while managing your MS.



"It's so important that people who live with MS are able to build families and not be held back in that respect by their disease."

RECOVERING FROM CHILDBIRTH

Now that your baby has arrived, it's time to allow your body to recover from pregnancy and childbirth, and for you to bond with your baby. The 6 to 8 weeks after childbirth are known as the **recovery period**.²⁻⁴ Some effects of childbirth may go away within a week of giving birth, while others may take months.³

The amount of time it takes to recover is different for each mother, with or without MS. Women with MS may be more likely to have an assisted birth (with help from forceps or a 'suction cup') or a Caesarean section (C-section).^{5,6} If you give birth by C-section, you may need longer to recover.⁷

Your doctor will probably want you to have a check-up appointment 6 to 8 weeks after you give birth, to see how your recovery is going.^{3,4}



Call your doctor if you are concerned about any neurological issues during your recovery period.

Here are some things you may find helpful during your recovery		
Pain medication	Medication can help you to manage any pain during your recovery. Speak to your doctor for advice. Always follow the instructions and don't take more than the recommended dose ⁸	
Haemorrhoid cream or suppository	If you have haemorrhoids, speak to your doctor. They may suggest a cream or suppository that will ease the discomfort ⁸	
Stool softeners	Constipation is common after childbirth, and straining to go to the toilet can make haemorrhoids worse. Speak to your doctor who may be able to recommend a medication to make it easier to go to the toilet ⁸	
Shallow baths or spray bottle	Regularly having a shallow bath or using a spray bottle filled with water could help relieve swelling and help with irritation from haemorrhoids or other childbirth-related vaginal issues. A spray bottle is convenient for providing quick relief after going to the toilet ⁸	
Cold compress	An ice pack or ice cubes wrapped in a towel can help manage the swelling and discomfort caused by haemorrhoids or episiotomy scars ^{8,9}	
Nipple ointment	Breastfeeding can cause your nipples to become sore, dry and cracked. Lanolin nipple creams can help provide relief and there is no need to wipe or wash it off before breastfeeding ¹⁰	
Breast pads	Wear in your nursing bras to help absorb any breast milk and protect your clothes from any leaks ¹¹	
Maternity pads	You may bleed a lot after giving birth, whether it's vaginal bleeding or bleeding from episiotomy scars. Maternity pads are longer, softer and more absorbent than sanitary pads ^{12,13}	

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"Don't stress yourself with being a perfect mother... Try to relax, focus on yourself, and find out what is good for you (do yoga, read a book, meditate, or just sleep)."



WILL I HAVE A RELAPSE AFTER MY BABY IS BORN?

Around 1 in 10 women may have a relapse within the first 3 months after their baby is born.¹⁴ You may be less likely to have a relapse after giving birth if, throughout the 2 years before getting pregnant, you were taking a medication for MS or your MS was stable.¹⁴ How you deliver your baby (whether you have a vaginal birth or a C-section) will depend on your labour and won't affect your risk of having a relapse after the birth.¹⁵

If you had mild MS before and during your pregnancy, your neurologist will probably monitor you closely and advise you to start taking a medication for MS again if you need to.¹⁶ If you had very active MS before your pregnancy, your neurologist may suggest that you start taking a medication for your MS again as soon as possible after giving birth. If you had relapses when you were pregnant, this doesn't mean you will have relapses during your next pregnancy.¹⁷ **Every pregnancy is different.**



"I was concerned about relapsing after having the baby. I wondered how soon a relapse would happen and how bad it would be or if I would need extra help. But I knew that worrying about it wouldn't stop a relapse, so I tried not to let it get me down."



After your baby is born, you may feel like your MS symptoms are worse. You may feel very tired, low or depressed, or have problems urinating.¹⁸ If you have any concerns, please speak with your doctor.

WILL MY MS GET WORSE AFTER MY BABY IS BORN?

After giving birth, you may have less energy, feel low or depressed, have bladder problems or have problems emptying your bowels. These are all common symptoms felt by women after giving birth. However, they may also be signs of your MS getting worse,¹⁸ and it is difficult to distinguish between the two. Fatigue (overwhelming tiredness): Whether you have MS or not, taking care of a newborn can be very tiring. You'll need to develop new skills and adapt your lifestyle in order to care for your baby, all while losing sleep.^{19,20} It's important to manage your fatigue, as it could make your MS symptoms worse.^{18,21} It's important to accept help from your family, friends and healthcare team so you can get some muchneeded rest.²²

"You never know how it feels not to sleep for weeks, to care for your ill children while you try to handle your job, while there is a possibility that your disease may get worse. This is exhausting. These are the moments when I feel as if I am not a healthy mother, that there is a disease. These are the moments when I struggle."



"Don't be shy in asking people for help if you need to sleep for an hour or so."

"Get sleep, whatever way you can. If anyone offers to take the baby so you can sleep, let them."



• **Depression:** Looking after a baby can have a huge effect on your emotional health. About one in five mothers experience depression within the first 6 months after giving birth.¹⁸ Studies have suggested that mothers with MS are at even higher risk, with **twice as many mothers with MS** experiencing postnatal depression compared with mothers without MS.^{23,24} It's **important to be aware of the signs** and to get checked for depression.¹⁸



Call your doctor if you think you are experiencing any signs or symptoms of depression after giving birth.

Accepting help from your support network can help to prevent or ease postnatal depression. Your family and friends can be a great source of help, especially in the early stages of caring for your baby.¹⁹

• Other common symptoms after giving birth

Bladder issues and problems urinating¹⁸

Mums often experience hair loss in the few months after giving birth $^{\rm 25}$

Ask your neurologist about symptoms you may experience after childbirth, and how these symptoms may trigger an MS relapse.¹⁸



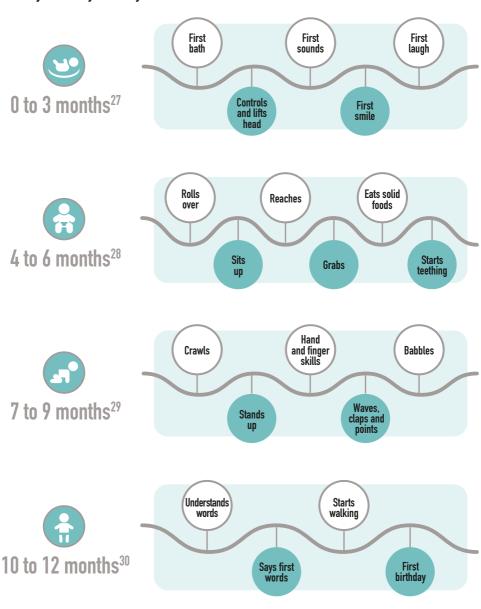
Call your doctor if you notice your MS getting worse or if you have any new symptoms that worry you.

CARING FOR A NEWBORN

Caring for a newborn, while taking on the challenges of housework, job-related stresses and other life issues, can put a lot of pressure on a mother.

General tips for mums with MS on caring for a new baby²⁶

- Call on your support network when you need to! Family and friends can come in handy when you are feeling overwhelmed or too tired to safely care for your baby.
- Sleep when your baby sleeps. Don't forget to ask for help when you're feeling exhausted. Your support network can help to care for your baby while you rest.
- Try to set up all of your baby equipment (toys, cot, furniture and so on) before the birth. Putting together baby equipment can be overwhelming and exhausting, and can be even more stressful with a crying baby around.
- Set up a chair close to the changing table, especially if standing causes fatigue. Portable cribs often have changing table attachments that tend to be lower, making it easier for you to sit while using them.
- Get a baby wrap or carrier made from lightweight material. This will help keep your arms and hands free, reducing muscle fatigue from holding the baby.
- Choose a sturdy and lightweight stroller designed to avoid tipping. Look for air-filled tyres and check the weight and folding mechanism before buying one.
- **Do some research to find the best lightweight car seat** that meets your needs. Visit a baby store and try lifting the car seats before buying one. Remember that adding a baby to the car seat will make it heavier.
- Some manual wheelchairs can be altered to allow you to attach a car seat. If you want to do this, find a professional who specializes in wheelchair modifications to make sure it is safe and appropriate for you.
- Smartphone apps can help you manage sleep and feeding schedules and doctor's appointments.
- Try a backpack-type diaper bag, to help improve your posture and reduce the risk of falling over if the bag is too heavy. It will also mean your hands are free to hold your baby.



The following timeline shows some important milestones in your baby's first year:

USING YOUR SUPPORT NETWORK

It's important to have a support network to help you take care of yourself and your child.

Friends and family	Ask your friends and family to help you look after your baby or to help with household chores. ²²
Neurologist, MS nurse and medical team	Your neurologist, MS nurse or medical team (doctors, midwives and so on) may be able to give you special advice on ways to take care of your baby based on your MS symptoms (for example, using a temperature monitor in your baby's bath, and a baby sling to carry your baby). ³¹ If you have any concerns about your baby, speak to your baby's doctor.
Local health services and support groups	Local health services and support groups are available to offer advice and services. ²²



"I got a home help [aid] through my health insurance – and that was really good help. During hard times with less sleep, I have a deal with my husband that I would sleep in the guest room with ear plugs so I could get some rest."



IF MY NEUROLOGIST ADVISED ME TO STOP MY MEDICATION FOR MS DURING PREGNANCY, CAN I RESTART IT AFTER GIVING BIRTH?

You may be at risk of a relapse after giving birth, so it's important to think about when to restart your treatment.^{14,16} **How soon you restart your treatment may depend on how severe your MS is.¹⁶** If you had very active MS before you got pregnant, you may need to restart your MS treatment as soon as possible after giving birth.^{6,16} If you had mild or moderate MS before and during your pregnancy, you may not need to restart your treatment immediately after giving birth, but you will need to be monitored.¹⁶



Call your doctor if you want to restart your treatment. You and your neurologist can decide together which medication is right for you.



"I decided to restart my treatment when I felt ready, about 3 weeks after my baby was born."

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BREASTFEEDING

CAN I BREASTFEED MY BABY, AND WILL IT AFFECT MY MS IF I DO?

Experts recommend that all mothers exclusively breastfeed their babies for the first 6 months of life, if possible.³² Breastmilk contains all of the nutrients that your baby needs.³² As long as your MS is stable and remains stable, **you can breastfeed if you choose and are able to.**³³ Research showed **that exclusive breastfeeding may reduce the risk of an MS relapse** within the first 6 months after giving birth, when compared with bottle-feeding with formula.³⁴ Although exclusive breastfeeding may not be protective in all cases, there is **no evidence that breastfeeding will make your MS worse.**³⁵

Breastfeeding may take some time to get used to. It may be uncomfortable at first,³⁶ and some mothers find it difficult to get their baby to latch on to the breast.³⁷ With time, you will learn which breastfeeding positions work best for your baby and are most comfortable for you.³⁸ If after several attempts you're still having trouble with breastfeeding, **discuss this with a breastfeeding consultant or your midwife**. They can advise you on how to overcome this.³⁷



"I was having trouble breastfeeding and was feeling immensely guilty. When I saw the lactation consultant, she was so understanding."

- It's important to make sure that you and your baby are comfortable when breastfeeding. Create a nursing station! Get a comfortable chair, some snacks, water and your favourite book. Don't forget some nursing pads and burping cloths, because you're likely to need those too.³⁹
- Make sure that you have back support, pillows to support your arms and the baby, and a footrest.⁴⁰
- Position your baby's nose level with your nipple, so that they'll have to tilt their head back when they latch on.^{40,41}
- Try different breastfeeding positions to see which work best for you and your baby.^{40,41}



BOOKLET

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Some mothers choose not to breastfeed their babies. Reasons

for choosing not to breastfeed can vary, from discomfort to restrictions based on health.⁴² Whatever the reason, if you decide breastfeeding isn't right for you, there are many different baby formulas available, including dairy-free products.

"I breastfed all of my children, because I wanted to. In the beginning it didn't work, but then [the baby and I] got used to it. Don't stress yourself to breastfeed. Sometimes it is better for both [you and the baby] to not breastfeed and just relax."





"Bottle feeding can be very handy. Anyone can feed the baby. If breastfeeding, store some milk also, if possible, so that others can feed the baby while you rest."

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Research showed that **at least one in five mothers with MS had a relapse** within 6 months after giving birth, **regardless of whether they only breastfed or if they bottle-fed their baby with formula.**³⁴ If you have a relapse, you may need to start your MS treatment again. If you are breastfeeding, you and your neurologist can decide together which medication is best for you to take.³³

LOOKING TOWARDS THE FUTURE

There are lots of things to look forward to as your child grows up, but it's important to remember that your condition may also change with time,⁴⁹ and to think about how it might affect how you care for your child.

- If you have a partner, include them in all your conversations with your medical team.
- Talk to your family and friends about how they might be able to help you.

"Ultimately, deciding to have a baby was the outcome of many, many conversations with my husband."



"Don't be afraid of the future. Decide in the present, because you never know the development of your MS. If you are ready to have a baby now, don't think of all the impairments the MS might cause. You don't know if it will really happen."

"I thought MS should not be a reason not to become a mother – I won't let the MS win!"



- Where can you find help?
 - Family doctor
 - Local health services and support groups
 - Patient support programmes
 - Partner, friends and family
 - Blogs, chat groups, Instagram or YouTube channels hosted by parents with MS
 - Maternity team
 - Local MS society, if one is available in your region
 - Other mums with MS

WHEN CAN I HAVE ANOTHER BABY?

You can try for another baby when you feel ready,¹⁷ just remember that every pregnancy is different. Having a relapse during a pregnancy doesn't necessarily mean you would have a relapse during a future pregnancy.¹⁷ The risk of a relapse during a future pregnancy isn't affected by how long you wait between pregnancies.¹⁷

It's important to discuss your future family plans with your neurologist, as this may affect your MS treatment plan. Your neurologist or MS nurse may ask you to wait until your MS is under control with treatment before you start trying for another baby.^{14,16}

"Sometimes I struggle, and I am not the perfect mum – but every moment is worth it."

"Our family's life is busy but typical."





"We are content just watching our baby grow, and my husband and I are developing a relationship that is stronger than ever."

At the end of this booklet we have included a blank page for you to write down any questions you may have for your neurologist.

MORE INFORMATION

Where can I get more information?

- Your neurologist and gynaecologist
- Your family doctor
- Your MS treatment patient support programme (if one is available near where you live)
- Your local MS society's website (if a local MS society is available near where you live)
- Blogs, Instagram, YouTube channels and social-media chat rooms hosted by other mums with MS

SEE THE OTHER BOOKLETS IN THE SERIES FOR MORE INFORMATION

- Booklet 1: I am trying for a baby
- Booklet 2: I am pregnant

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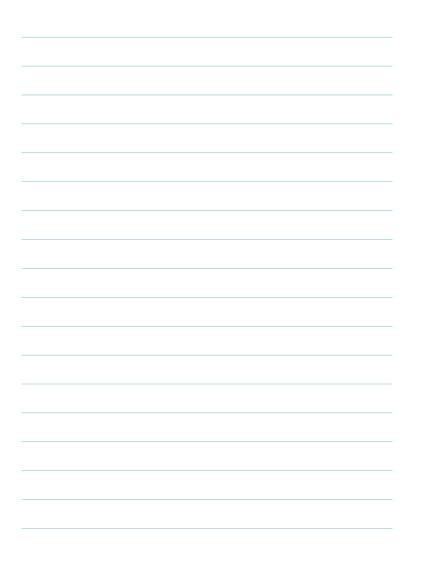
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Keep this booklet with you. If you have any questions, write them down here so that you remember to ask them at your next appointment.





Disclaimer

This booklet is intended to be used as a general guide. The information in it should not replace medical advice, independent judgement or proper assessment by a doctor who has considered your particular circumstances and needs. This booklet reflects information that was available at the time it was prepared, and you should consider it alongside any information that has recently become available. Merck does not accept any liability to you as a result of using the information in this booklet. Always seek the advice of your treating Healthcare Professional if you have any questions regarding your individual treatment plan.

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Merck is proud to support women living with multiple sclerosis (MS), who don't let their condition stop them from living the life they choose, which includes having children if they want to. By providing supporting information on MS, pregnancy, childbirth and lactation, Merck hopes to encourage women to have open discussions on this important subject.

At Merck, we are committed to improving MS from the inside out. #MSInsideOut

With the friendly support of Merck