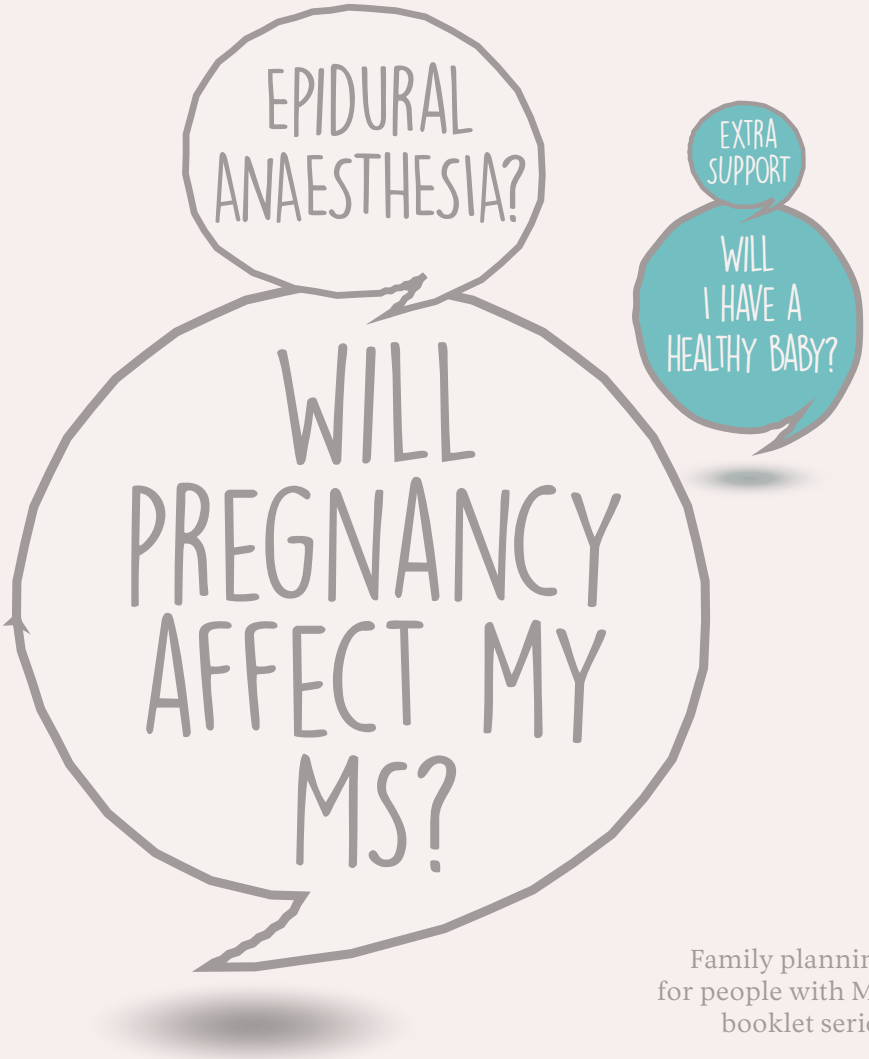
ENTER

I am pregnant



Family planning
for people with MS
booklet series

This booklet has been designed for easy navigation. Turn pages by using the back/forward arrows at the bottom of each page. You can also jump to a specific topic by clicking on the hyperlinked item in the Contents. To return to the Contents page, click on the arrow in the top right corner of each page.

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

This is the second 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.
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CONTENTS

Congratulations! You're pregnant! 2
- Things you can look forward to over the next 9 months 2
- Who should I tell that I'm pregnant? 5

What to expect 6
- Symptoms you might experience 6
- Urinary infections 8

Pregnancy and MS 9
- How will pregnancy affect my MS? 9

Relapses 9
- Will I relapse during pregnancy? 9
- Will I have a relapse after my baby is born? 11

MS treatment 12
- Should I stop taking my drug for MS now that I'm pregnant? 12
- Are there any MS drugs that I can take while I'm pregnant or breastfeeding? 13
- What if I have a relapse while I'm pregnant? 16

Hospital bag checklist 16

Giving birth 17
- Am I in labour? 17
- How will MS affect my labour? 17
- What pain relief can I take during labour? 18
- My birth plan 20

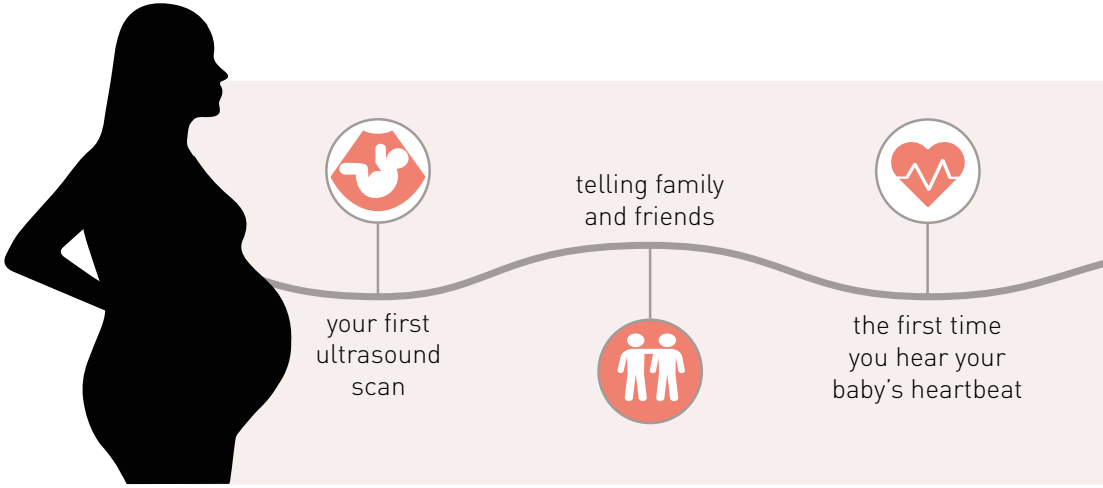
References 24

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."

the first time
you feel your baby move
(at around 18 to 20 weeks)

decorating the nursery and
buying your baby's first toys
and clothes



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 drug 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.

"I was worried I might relapse." – Julia

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 drug 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

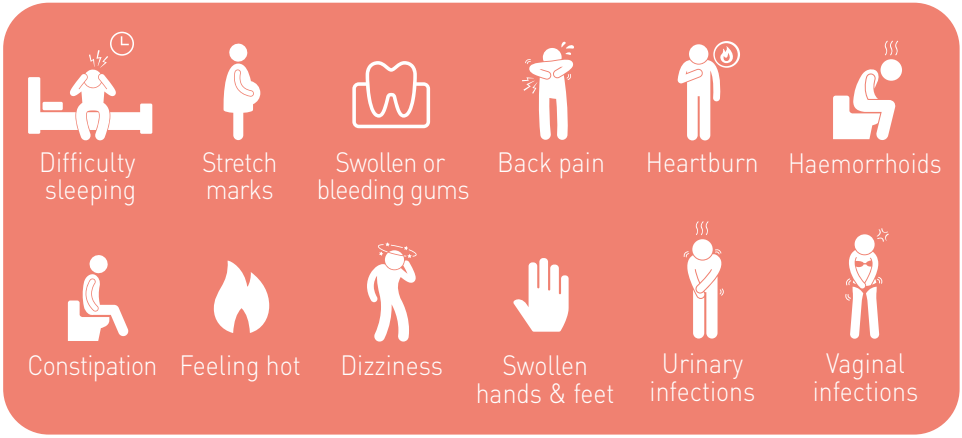
FIRST TRIMESTER
(Weeks 0 to 12)



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]



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 drug 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 drug 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 drug 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 drug 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 drug 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 DRUG FOR MS NOW THAT I'M PREGNANT?

There are some drugs 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 drug for MS while you are pregnant, they will explain your options to you.

ARE THERE ANY MS DRUGS THAT I CAN TAKE WHILE I'M PREGNANT OR BREASTFEEDING?[10]

(note: drugs listed in alphabetical order)

Alemtuzumab*[28]	Women of childbearing potential have to use effective contraception when receiving a course of treatment with alemtuzumab and up to 4 months after each course of treatment Alemtuzumab should be administered during pregnancy only if the potential benefit justifies the potential risk to the foetus Breastfeeding should be discontinued during each course of treatment with alemtuzumab and for 4 months following the last infusion of each treatment course. However, benefits of conferred immunity through breast milk may outweigh the risks of potential exposure to alemtuzumab for the suckling newborn/infant
Cladribine Tablets*[25]	Women of childbearing potential must prevent pregnancy by use of effective contraception during treatment with Cladribine Tablets and for at least 6 months after the last dose of Cladribine Tablets Cladribine Tablets are contraindicated during pregnancy It is not known whether cladribine is excreted in human milk. Because of the potential for serious adverse reactions in breastfed infants, breastfeeding is contraindicated during treatment with Cladribine Tablets and for 1 week after the last dose
Dimethyl fumarate*[29]	Dimethyl fumarate should be used during pregnancy only if clearly needed and if the potential benefit justifies the potential risk to the foetus A decision must be made whether to discontinue breastfeeding or to discontinue dimethyl fumarate therapy

*EU Summary of Product Characteristics

continued on next page

ARE THERE ANY MS DRUGS THAT I CAN TAKE WHILE I'M PREGNANT OR BREASTFEEDING?

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Fingolimod*[26]	Women of childbearing potential must use effective contraception during treatment and for 2 months after discontinuation of fingolimod Fingolimod is contraindicated during pregnancy Due to the potential for serious adverse reactions to fingolimod in nursing infants, women receiving fingolimod should not breastfeed
Glatiramer acetate†[30]	As a precautionary measure, it is preferable to avoid the use of glatiramer acetate during pregnancy unless the benefit to the mother outweighs the risk to the foetus A risk to newborns/infants cannot be excluded. A decision must be made whether to discontinue breastfeeding or to discontinue/abstain from glatiramer acetate therapy, taking into account the benefit of breastfeeding for the child and the benefit of therapy for the woman
Interferon beta[31–34] Subcutaneous interferon beta-1b* Intramuscular interferon beta-1a* Subcutaneous interferon beta-1a* Peginterferon beta-1a*	If clinically needed, the use of interferons may be considered during pregnancy. Experience with exposure with the second and third trimester is very limited Limited information available on the transfer of interferon beta-1a into breast milk, together with the chemical/physiological characteristics of interferon beta, suggests that levels of interferon beta-1a excreted in human milk are negligible. No harmful effects on the breastfed newborn/infant are anticipated. Interferons can be used during breastfeeding

*EU Summary of Product Characteristics; †UK Summary of Product Characteristics

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ARE THERE ANY MS DRUGS THAT I CAN TAKE WHILE I'M PREGNANT OR BREASTFEEDING?

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Natalizumab*[35]	If a woman becomes pregnant while taking natalizumab, discontinuation of the medicinal product should be considered. A benefit-risk evaluation of the use of natalizumab during pregnancy should take into account the patient's clinical condition and the possible return of disease activity after stopping the medicinal product Natalizumab is excreted in human milk. The effect of natalizumab on newborns/infants is unknown. Breastfeeding should be discontinued during treatment with natalizumab
Ocrelizumab*[36]	Women of childbearing potential should use contraception while receiving ocrelizumab and for 12 months after the last infusion of ocrelizumab Ocrelizumab should be avoided during pregnancy unless the potential benefit to the mother outweighs the potential risk to the foetus It is unknown whether ocrelizumab/metabolites are excreted in human milk. Available pharmacodynamic/toxicological data in animals have shown excretion of ocrelizumab in milk. A risk to neonates and infants cannot be excluded. Women should be advised to discontinue breastfeeding during ocrelizumab therapy
Teriflunomide*[27]	Women of childbearing potential have to use effective contraception during treatment and after treatment as long as teriflunomide plasma concentration is above 0.02 mg/L Teriflunomide is contraindicated in pregnant women Animal studies have shown excretion of teriflunomide in milk. Teriflunomide is contraindicated during breastfeeding

*EU Summary of Product Characteristics

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, your neurologist may discuss the risks and benefits of treating you with steroids 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 checklist 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 and childbirth 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
None

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

Note: The benefits and risks of each type of pain relief should be considered on a case by case basis.

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 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)

- You may be able to deliver your placenta naturally or you may need an assisted delivery.

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 print out and 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



"I had an epidural." – 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)
- The website for your local MS society, if you have one
- 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.



YOU

- [ ] Your hospital paperwork for both your pregnancy and your MS, including a note from your neurologist to the medical team looking after you during the birth, explaining that your MS does not affect what pain relief you can have and that a long labour is not advised for women with MS

- [ ] Your birth plan
- [ ] Any medicines you take
- [ ] Enough loose and comfortable clothes for a few days' stay in hospital
- [ ] Maternity pads
- [ ] Disposable underwear
- [ ] Nursing bra (if you would like to breastfeed)
- [ ] Snacks and drinks*
- [ ] Toiletries
- [ ] A book/magazine

- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____

*Please check with your hospital what food/drinks you are allowed to take in with you

continued on next page

HOSPITAL BAG CHECKLIST

continued from previous page

YOUR BABY

- [ ] Vests
- [ ] Baby grows and sleepsuits
- [ ] Hats, socks and booties
- [ ] Going-home outfit and blanket
- [ ] Nappies
- [ ] Wipes
- [ ] Car seat
- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____

YOUR PARTNER

- [ ] 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
- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____
- [ ] _____

*Please check with your hospital what food/ drinks you are allowed to take in with you

MY BIRTH PLAN

Due date _____

Birthing partner's name and contact details

Labour and birth

Pain relief

continued on next page

continued from previous page

MY BIRTH PLAN

Unexpected situations (for example, assisted births)

Other things that are important to me



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.

CLOSE

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.

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

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