

Pregnancy and MS

Multiple sclerosis (MS) is most often diagnosed between the ages of 20 and 40, when you may be considering having a child. Deciding whether to start or add to a family is often a complicated process, and MS raises a host of other questions to consider - the potential risks of medications before or during pregnancy, the effect of pregnancy on your MS, the possibility of your children getting MS and whether you'll be able to breastfeed.

You may also have concerns/questions around how you'll cope practically and emotionally living with MS whilst pregnant or later, with a baby and with children.

This information sheet covers some of the more common questions. If you're considering pregnancy (or are pregnant), you should use this information plus communication with your healthcare team to feel more comfortable making decisions to suit your individual circumstance.

MS and pregnancy

Will MS impact on your ability to conceive?

There is no evidence that MS has a direct effect on fertility, which means that if you have MS you have as good a chance of conceiving with your partner as a couple without MS.

However, some people do experience sexual difficulties as a result of their MS. Examples are erectile dysfunction in men, or a reduction in libido for women. These can impact on your sexual relationship, which will have an impact on your chances of conceiving a baby.

Additionally, just as in the general population, problems conceiving can occur, and some couples (including those where MS is a factor) may have difficulty. Treatments for infertility may increase MS disease activity so in-depth discussion with your healthcare team and reproductive medicine team to explore all the pros and cons of a treatment is important.

What is the impact of your MS on the pregnancy?

For most women, MS doesn't make any significant difference to their pregnancy. If you have MS you're no more likely to experience complications like miscarriage, birth defects or stillbirth than a woman who doesn't have MS.

What is the impact of the pregnancy on your MS?

If you have relapsing remitting MS (RRMS), you're less likely to have a relapse during pregnancy particularly in the last three months, although the risk of relapse does increase in the first three months after the birth of your baby. The individual patient's experience with relapses following any previous pregnancy is a good indicator of the risk of relapse following the birth.

It's thought that relapse rate is reduced during late pregnancy in part because of the effect of pregnancy hormones, notably oestrogen, which suppress the immune system to ensure that the body will carry a growing baby without rejecting it. There is also some indication that treatment with a Disease Modifying Therapy (DMT) for <u>at least one year prior to conception</u>, reduces the risk and severity of a relapse following birth of the baby.

Overall, relapse rate has been found to be similar during the pregnancy 12 months (nine months of pregnancy and three months following the birth) as in a non-pregnancy year. Additionally, research studies in the last five years suggest pregnancies in women with RRMS are associated with less long-term disability.

It's difficult to predict the severity of any relapse that you might experience during pregnancy, but as far as is known, relapses don't affect the baby. Tell your MS nurse or consultant if you do have a relapse, whether it's severe or not.

There isn't enough data on pregnancy in women with progressive MS to give an accurate indication of its effect on this type of multiple sclerosis.

How will pregnancy affect my (MS) symptoms?

Most women with MS feel well during their pregnancies, and experience no new problems. However, some symptoms that occur in MS also occur in pregnancy, and it may be difficult to distinguish the cause.

Fatigue is often a problem in early pregnancy and MS fatigue may therefore appear to worsen. Heat sensitivity may also increase during pregnancy, which may make fatigue worse. Women often find that they don't sleep as well during pregnancy, further contributing to increased fatigue.

Bladder symptoms such as frequency and urgency can increase because of pressure on the bladder from the uterus. It's also important to be vigilant about urinary tract infections. In late pregnancy, mobility problems can worsen due to the increasing weight of the baby and changes in posture.

Women's experiences of pregnancy vary greatly and any new or worsening symptoms should be discussed with your midwife, GP or MS nurse.

Some women are concerned about the effect of pregnancy on symptoms postnatally, particularly bladder symptoms. Research showed that there was no difference in bladder problems experienced between women with MS who had had children, and women with MS who had never given birth.

MS medications and pregnancy

A number of medications for MS, both DMTs and those for symptom management, are not recommended for use by women during pregnancy or when breastfeeding. In some cases, medications have been shown to be harmful to the developing baby or, more often than not, the effects on the unborn child are simply unknown.

If you're planning a family, or find you're pregnant, you should discuss your MS medications with your neurologist.

Should I stop taking medication when trying to conceive?

There is no <u>disease modifying drug</u> that has been proven to be completely safe during pregnancy. It is recommended that any woman who is taking a disease modifying drug treatment for MS, should seek guidance from her neurologist, if possible, <u>prior to conception</u>. This discussion will focus on what medication you are on and how active your MS is. Your neurologist will make recommendations as to changes needed prior to conception or may even recommend that you stay on the medication.

Can I take steroids whilst I'm pregnant?

Steroids carry some risks and so it's thought that these should be avoided, particularly during the first three months of pregnancy when the foetus is developing very rapidly. However, if a severe relapse occurs, it may be decided - in consultation with your healthcare team - that the benefits outweigh any potential risks of treatment.

Labour and Delivery

Where can I give birth?

In Australia there are various options for where to give birth, including public or private healthcare facilities, plus birth centres. In some cases, medical conditions will determine that a pregnancy is deemed high risk and as a precaution, high risk pregnancy is not managed in low risk facilities like birth centres or a home birth.

Your MS and any other factors, including your preference, should be considered when deciding where to give birth. It's best to research your options in the early stages of pregnancy.

Will MS affect my labour or delivery?

Generally, delivery is no more complicated for women with MS than it is for women without MS.

In most cases MS does not affect labour or delivery, but there have been some cases where women have had trouble detecting that they are experiencing contractions, due to reduced nerve function. The risk of fatigue is also likely to be higher for women with MS and sometimes this can increase the chance of an assisted delivery (e.g. the use of forceps or vacuum-assisted vaginal delivery during birth).

Many pregnant women choose to make a 'birth plan' outlining their wishes during labour and postbirth around such things as procedures, atmosphere and preferred place for the birth. If you have MS this can be even more important, as not all health professionals attending your labour will be familiar with the condition.

You can also make a plan for pain relief. For example, it may be useful to document whether you would accept epidural pain relief, as some health professionals on the day may not have MS experience and can be reluctant to give this. Discussing with your healthcare team including obstetrician or midwife and your MS nurse can be really valuable. You should be proactive and ask for what you want.

There is little research about whether different types of delivery are better suited for women with MS. For most women, including most women with MS, a vaginal delivery is suitable. However, any concerns about positions, or managing fatigue during labour, should be discussed with a midwife in advance. If you experience spasticity or spasms it's really important to discuss this with your midwife and plan for the birth, exploring possible birth positions that will be helpful; and have this documented in your birth plan. Some women find the option of a water birth helpful when heat sensitivity is part of their MS. If fatigue is a problem, it may be possible to arrange an early epidural to allow you to rest in the early stages of labour - this could form part of your birth plan.

At delivery, the safety of both mother and child is paramount and there may be medical reasons for an assisted delivery - for example forceps or ventouse (suction cup) delivery - or delivery by caesarean. Whilst in some cases women may choose to deliver by caesarean, recovery from this procedure frequently takes longer than from a vaginal delivery, and involves restrictions on activities such as driving a car and heavy lifting.

If you have MS, we recommend that you discuss your labour and birth plan with your obstetrician or midwife early in your pregnancy. Midwives are usually very supportive of a woman's personal choice for delivery. It can also be reassuring to speak to other people with MS who are pregnant or have given birth in the past.

What pain relief is available?

Generally, women with MS can accept most types of pain relief during labour, such as pethidine, entonox (gas and air) and epidural anaesthesia. Epidurals are safe and will not increase the chances of a relapse or impact on your level of ability after the baby is born. General anaesthetics are also safe and may be an option for women requiring a caesarean.

TENS machines are available for pain relief in the early stages of labour. However, anecdotal evidence suggests that TENS machines can trigger lower limb spasm in some women with MS during labour, so it may be worth discussing this with health professionals in advance.

Breastfeeding and MS

How to feed a newborn baby is, and should be, a personal choice. You may have understandable concerns about breastfeeding. But MS cannot be passed through breast milk and studies on the course of MS suggest either no effect, or even a possible decrease in the relapse rate is associated with breastfeeding.

However, fatigue can be a real issue for all new mothers, especially those who are breastfeeding. When that is coupled with MS fatigue it is an important consideration.

Because of the increased risk of relapse in the first few months after birth, it may be worth considering expressing and storing some breast milk. Additionally, stored milk can also be used by other members of the family to feed your baby, which allows you some extra rest time or a break from night feeds.

Often chosen for their ease and efficiency, electric breast pumps can conserve energy compared with using a manual breast pump. Electric breast pumps express your milk faster.

When feeding, find a comfortable position to hold your baby that doesn't make your arms and back ache. Have cushions or pillows nearby to support you and your baby.

It's good to discuss your feeding options with your MS nurse and/or midwife before your baby is born, so that they can provide appropriate support and advice. You may also access support and/or advice from the <u>Australian Breastfeeding Association</u>, who can put you in touch with other relevant services.

Medications and breastfeeding

Can I take steroids when breastfeeding?

Steroids have been shown to cross into breast milk, but there is very little research that has explored the high doses used in treating MS relapse, so currently women are advised not to breastfeed whilst taking steroids. You may choose to express as much milk as possible before starting the course of treatment and store this for use during the treatment - usually five days for oral steroids or three days

if taken intravenously. Milk can be expressed and discarded during the actual treatment period to ensure you maintain your milk supply. Breastfeeding can start again between one and two days after the end of treatment - your MS nurse and neurologist will determine the exact timings with you.

When can I start MS medication after the birth?

Some disease modifying therapies can cross into breast milk, but there has not been a great deal of research in this area. Your healthcare provider will be able to advise on the most appropriate medication for your circumstances, however, if your MS is very active and you are at significant risk of relapse, you may choose to stop breastfeeding and opt for bottle feeding to enable you to recommence DMT.

The decision whether to resume disease modifying treatment immediately after the birth or not, needs to be considered against the advantages of breastfeeding. A few things to consider:

- You're not protected by medications during the time when relapse is more likely to occur.
- Exclusive breastfeeding has been shown to reduce after-birth relapses.
- Fatigue is worse among women with MS, so breastfeeding may be less practical, especially as fatigue reduces milk protection.
- Breast milk has been shown to protect against a range of diseases and illnesses in babies.

If you aren't able, or don't want, to breastfeed then you shouldn't feel that you have in some way failed your child.

The first few months

Post-natal care

Once your baby is born, your midwife will visit you the day following discharge from hospital. There may be a further visit before the care is then transferred to the maternal health nurse, who has a duty to monitor the general health and wellbeing of the whole family, not just the baby. If possible, it may be worth trying to meet your maternal health nurse before the baby is born. Your GP is also responsible for monitoring both mother and baby.

It's good to seek assistance

As for anyone with a new baby, it can be valuable to make the most of any offers of help - from friends, family and/or perhaps, through community care services or your healthcare team. Additionally, for people living with MS, it's important to consider the increased possibility of relapse in the first few months and the layering of new parent fatigue with MS fatigue.

You may need help with household tasks, night feeding, or appreciate an opportunity to get some additional sleep to minimise the fatigue associated with both MS and being a new parent.

One research study found that having help available for the whole of the first year, reduced the number and impact of symptoms that a new mother with MS experiences and increases her ability to function normally. While this may not be feasible for everyone, developing a network of potential helpers who may be available at short notice may be useful.

Your nutrition

All new parents should adhere to a nutritious diet to enable recovery from childbirth, maintain their optimal wellbeing and support breastfeeding. Additionally, if your MS management includes specific dietary requirements, you may need to put some extra strategies in place to enable this to continue.

Some tips may include:

- Prepare some meals pre-birth and freeze individual portions so you're not worrying about cooking post-birth.
- Have healthy snacks near to hand as breastfeeding can increase your appetite.
- Online grocery shopping may be an option.
- Don't forget to accept help from family and friends, especially in the first few weeks.

Managing specific symptoms

If you experience sensory disturbances in your hands, you should use a temperature monitor in the baby bath. For those who experience weakness in upper limbs - consider a baby sling to hold your baby.

If you experience fatigue and live in a two-level home, try to have a baby change mat, nappies, wipes, spare baby clothes etc. on each floor. And, as with any new parent, if possible sleep or rest when your baby does in the first few weeks and accept help when it's offered!

Other general questions

Can I pass MS on to my child?

This is a common question. Although MS has a genetic component, genes alone do not cause the condition, and the majority of children born to a parent with MS will not go on to develop MS. Studies have shown that as few as 1.2% of people with MS have a parent with MS.

What about contraception after my baby is born?

Post birth (especially if you are returning to MS medications), it's advised to commence contraception as soon as possible. Discuss these questions fully and any others with your doctors, so that you can make important decisions and the safest plan of action.

Support during pregnancy and when caring for a new baby

It's easy for anyone to feel isolated when caring for a new baby. Many people find it helpful to speak to other parents in a similar situation.

There are numerous Australian (and overseas) Facebook and other online pregnancy support groups (some are membership-based), where you can discuss a range of pregnancy and parenting topics and find services in your local community.

In this <u>blog</u> on the MS Australia website, Catherine Brooks shares her personal experience of pregnancy and MS (and tips), and touches on many of the questions raised in this information sheet.

The MS Australia <u>Uninterrupted</u> blog has a range of personal stories about the MS experience (including some about pregnancy).

Health visitors are a good source of information about local support groups for parents and babies. Your MS nurse may be able to help identify other new parents with MS. There are also several organisations that offer support and information for parents.

Information and assistance:

General

There is support available to help you manage your MS:

- Your GP/Midwife should be the first contact for any new questions related to pregnancy.
- Your neurologist, MS Nurse or other healthcare provider can help you to manage your MS during pregnancy and discuss the best approach for your individual circumstances.
- Contact your state MS organisations (details below) to access services including peer support and other resources.
- For information about MS and MS treatments visit www.msaustralia.org.au

Contact details for your state/territory MS organisations:

MS Limited (Victoria NSW ACT Tasmania)	1800 042 138	msconnect@ms.org.au	www.ms.org.au
MSWA (Western Australia)	1300 097 989	communications@mswa.org.au	www.mswa.org.au
MS Society SA & NT (South Australia NT)	1800 812 311	msassist@ms.asn.au	www.ms.asn.au
MS Queensland	1800 177 591	info@msqld.org.au	www.msqld.org.au

Other organisations

The following support services may be able to provide other advice (before, during and/or after pregnancy):

- Independent Living Centres 1300 885 886 <u>www.ilcaustralia.org.au</u> has a range of products to assist with day-to-day living including pillows to assist during pregnancy.
- Carers Australia 1800 242 636 <u>www.carersaustralia.com.au</u> provides information and advice to carers, their friends and families about carer support and services.
- Australian Breastfeeding Association 1800 mum 2 mum (1800 686 268) www.breastfeeding.asn.au/ provides support and information to enable mothers to establish and continue breastfeeding.
- The Department of Health's national Pregnancy, Birth and Baby helpline 1800 882 436 www.pregnancybirthbaby.org.au provides 24/7 free, confidential, professional information and counselling for women, their partners and families relating to conception, pregnancy, birthing and postnatal care.

General pregnancy websites:

- **Baby Centre** <u>www.babycenter.com.au</u> (Australian site but note US spelling in URL) helps new, expecting and prospective parents find information and support through medically reviewed information, and a community of supportive, helpful parents going through the same things.
- **Kidspot** http://www.kidspot.com.au/birth/pregnancy provides news, guidance, information and advice to help people through every stage from pregnancy to parenting teens.
- Some state/territory hospitals have dedicated pregnancy sections on their websites, such as Victoria's Royal Women's Hospital: https://www.thewomens.org.au/health-information/pregnancy-and-birth/
- Australian parenting website Raising Children http://raisingchildren.net.au/ is often recommended by GPs and health professionals as a reliable source of post-birth information, and includes a pregnancy section.

Sources: This fact sheet comprises material from previously published Australian MS Society leaflets plus Multiple Sclerosis (MS) UK Trust online resources (and associated references), and has been endorsed by a medical expert, MS nurse, a neurologist, midwife, and a young mother with MS with personal experience of pregnancy.

Disclaimer: This information was prepared by MS Australia. It is intended to provide useful and accurate information of a general nature and is not a substitute for medical advice.