

lupus  **FACT SHEET**

Lupus Canada

Pregnancy and Lupus

The peak incidence of systemic lupus erythematosus (SLE or lupus) occurs in women in their reproductive years (ages 15 to 45). Although lupus itself usually does not affect fertility rates, pregnancy planning is an important issue for women with this disease.

compared. This is especially important if you have a history of major organ disease, such as kidney involvement. Since the normal values for laboratory measurements are different during pregnancy, this baseline is important for the interpretation of later results.

Even as recently as the 1980s, women with lupus were often counselled not to become pregnant due to the risk of a disease flare and an increased risk of miscarriage. Approximately 20 to 25 percent of pregnancies in women with lupus end in a miscarriage compared to 10 to 15 percent of pregnancies in women without the disease.

Most women with lupus are able to carry their babies safely to term.

In particular, the anti-Ro antibody, which you should be tested for in your pre-pregnancy assessment, has been associated with heart rhythm disturbances in babies of mothers carrying this antibody. About a quarter of women with lupus have this antibody. It is linked to Sjogren's syndrome and may also be seen in people without autoimmune diseases. Keep in mind that the risk of any problem occurring is only about three percent.

Research and careful treatment have made it possible for more and more women with lupus to have healthy pregnancies. Although pregnancy with lupus may still be considered high risk, most women with lupus are able to carry their babies safely to term.

For most women, it is extremely important that the lupus be carefully monitored by an experienced multidisciplinary team so that abnormalities during pregnancy and post-partum are identified, diagnosed and treated promptly.

Planning and counselling should begin before you become pregnant. For the best chance of a healthy pregnancy, conceive when your lupus disease activity is low or in remission, or has been stable, minimally active or in remission for six months prior to conception, and you are taking only medications deemed safe during pregnancy (see sidebar).

For some patients, delivery must be planned at a hospital that can accommodate a high-risk patient and provide the specialized care that the patient and baby may need.

Lupus flare

One problem that can affect your pregnancy is the development of a lupus flare. In general, it is uncertain to what extent flares are caused by pregnancy. Flares that do develop often occur during the first or second trimester or during the first few months after delivery. Most flares are

An evaluation prior to pregnancy should consist of both a clinical and laboratory review so that your doctor has a baseline against which your lupus during pregnancy can be



mild and can be managed with small doses of corticosteroids.

Neonatal lupus

Babies born to women with lupus have no greater chance of birth defects than babies born to women without lupus.

However, about three percent of babies born to mothers with lupus will have neonatal lupus. This condition consists of a temporary lupus-like rash and abnormal blood counts, which are linked to the mother's antibodies passing in utero to the baby across the placenta. The good news is that neonatal lupus usually disappears by the time the infant is three to six months old and does not recur. Very rarely, babies with neonatal lupus are born with a heart condition. This condition is permanent, but it can be treated with a pacemaker.

Other possible complications

Pregnant women with lupus, especially those taking corticosteroids, are also likely to develop pregnancy-induced high blood pressure (hypertension), gestational diabetes and kidney complications.

Problems may include excessive weight gain, generalized swelling (edema), excess protein in the urine, severe headache and visual disturbances. Such developments may indicate a serious condition that requires immediate treatment, usually including delivery of the infant.

Breast feeding

Most medical professionals feel that it is important to try to breastfeed your baby as it is the ideal, low-cost way to provide nutrition in the first weeks or months of life. It takes time for mothers and babies to learn how to breastfeed, and it may take a few weeks to adjust. Because breastfeeding is often a challenge, ask your doctor or nurse for help as soon as you are admitted to the maternity ward, so that you do not become discouraged. Some individuals hire a lactation consultant; the staff on the maternity ward where you deliver can discuss this with you. Sometimes, though, breastfeeding may be difficult for the following reasons:

1. A premature baby may not be able to suck adequately. Feeding your baby through a tube at first and then by bottle may be necessary. However, you may still be able to pump your breast milk for your baby.
2. If you are taking corticosteroids, you may not be able to produce enough milk.
3. Some medications can pass through your breast milk to your baby. Talk to your doctor about whether or not breastfeeding is safe with the medications you are taking.
4. Because breastfed babies tend to eat more frequently than do bottle-fed infants, breastfeeding can be very tiring. Options

CARING FOR YOURSELF DURING PREGNANCY

- Keep all of your appointments with your primary doctor and your obstetrician.
- Get enough rest. Plan for a good night's sleep and rest periods throughout the day.
- Eat a sensible, well-balanced diet. Avoid excessive weight gain. Have your obstetrician refer you to a registered dietitian, if necessary.
- Take your medications as prescribed. Your doctor may have you stop some medications and start or continue others.
- Don't smoke or drink alcoholic beverages.
- If you're not already taking a folic acid supplement, now is the time to start. This B vitamin reduces the risk of neural tube birth defects. The most crucial time for fetal development occurs between five and 12 weeks, so you should start taking folic acid before you become pregnant and continue at least to the end of the first trimester. Prenatal multivitamins contain the necessary amount of folate (1 mg per day).
- Be sure your doctor reviews with you the normal body changes that occur during pregnancy. Some of these changes – such as extreme fatigue – may be similar to those that occur with a lupus flare. Although it is up to the doctor to determine whether the changes are normal or represent the development of a flare, you must be familiar with them so that you can report them as soon as they occur.
- If you are not sure about a problem or begin to notice a change in the way you feel, talk to your doctor right away.
- Ask your doctor about participating in childbirth preparation and parenting classes. Although you have lupus, you have the same needs as any other new mother-to-be.

include pumping breast milk so that a partner can help feed the baby by bottle; supplementing breastfeeding with formula; or switching to a bottle and formula entirely. Keep in mind that, depending on what type of formula you use, bottle-feeding can be as time-consuming as breast-feeding (or even more so) if one considers the time required for preparation, cleaning bottles, etc.

Be confident that whatever method you choose to feed your baby, it will be the right decision for everyone concerned.

Rheumatology drugs considered safe in pregnancy

Acetaminophen
Aspirin (81 mg/day)
NSAIDs until 28-32 weeks gestation
Prednisone
Chloroquine
Hydroxychloroquine
Azathioprine
Cyclosporine
Tacrolimus
Heparin
Nifedipine
Labetolol

Potential complications during pregnancy

Lupus flare

- ⇒ Increased pain
- ⇒ Morning stiffness
- ⇒ Fever
- ⇒ Development of rash that worsens
- ⇒ Stomach discomfort
- ⇒ Headache
- ⇒ Dizziness



PLANNING YOUR PREGNANCY

Awareness, monitoring and careful planning are the keys to a successful pregnancy. Before conceiving, discuss your decision with your doctor, as certain drugs should be discontinued prior to conception. Both you and your doctor should be satisfied that your lupus is under good control or in remission.

If your rheumatologist advises it, select an obstetrician who has experience managing high-risk pregnancies and is associated with a hospital that specializes in high-risk deliveries and has the facilities to care for a newborn with special needs.

Review your work and activities schedule. Be prepared to make changes if you are not feeling well or need more rest.

Consider your financial status. If you work outside the home, your pregnancy and motherhood could affect your ability to work.

Develop a plan for help at home during the pregnancy and after the baby is born. Motherhood can be overwhelming and tiring, and even more so for a woman with lupus. Although most women with lupus do well, some may become ill and find it difficult to care for their child.

Miscarriage

- ⇒ Cramping
- ⇒ Vaginal bleeding (spotting to heavy bleeding)

Pregnancy-induced hypertension

Mild

- ⇒ Blood pressure 140/90 mmHg and over during second half of pregnancy
- ⇒ Excess protein in the urine (proteinuria)
- ⇒ Mild, generalized swelling (edema)

Pre-eclampsia

- ⇒ Abdominal pain
- ⇒ Blood pressure 140/90 mmHg and over during second half of pregnancy
- ⇒ Excess protein in the urine (proteinuria)
- ⇒ Overactivity of physiological reflexes (hyperreflexia)
- ⇒ Swelling (edema), including face and hands

Eclampsia

- ⇒ All of the symptoms of pre-eclampsia
- ⇒ Seizures

Neonatal lupus

Baby experiences:

- ⇒ Transient rash
- ⇒ Transient blood count abnormalities
- ⇒ Heart block (disturbance in heart rhythm)



FOR MORE INFORMATION

- Lupus Canada: www.lupuscanada.org. This site includes electronic versions of the *Living Well with Lupus* fact sheets.
- *Lupus: The Disease with a Thousand Faces*, edited by Dr. Sasha Bernatsky and Dr. Jean-Luc Senécal, Key Porter Books (2004) ISBN 1-55263-603-8. Contact Lupus Canada to order this book.
- MedlinePlus Health Information: High Risk Pregnancy Resources:
<http://www.nlm.nih.gov/medlineplus/highriskpregnancy.html>
- The Motherisk Program at the Hospital for Sick Children, Toronto: www.motherrisk.org. Offers pregnant, planning and breastfeeding women answers to questions about the risk or safety of medications, herbs, diseases, chemical exposures and more.
- La Leche League Canada: www.lllc.ca. Mother-to-mother breastfeeding support.

Disclaimer

Systemic lupus erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from person to person and treatment is highly individualized. Patients are urged to contact their physician or healthcare professional with any questions or concerns they might have.

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