

LUPUS and pregnancy



THE LUPUS UK RANGE OF FACT SHEETS

Further fact sheets are available as follows:

- LUPUS Incidence Within The Community
- LUPUS A Guide For Patients
- LUPUS The Symptoms and Diagnosis
- LUPUS The Heart and Lungs
- LUPUS and the Brain
- LUPUS and the Kidneys
- LUPUS The Joints and Muscles
- LUPUS The Skin and Hair
- LUPUS The Mouth, Nose and Eyes
- LUPUS and the Feet
- LUPUS Fatigue and your Lifestyle
- LUPUS and Men
- LUPUS and Light Sensitivity
- LUPUS and Blood Disorders
- LUPUS and Medication
- LUPUS and Associated Conditions

LUPUS UK is the registered national charity caring for people with lupus and has some 7,000 patients in membership who are supported by 30 regional groups.

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Please contact our national office should you require further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

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My baby had a rash when it was born, does this mean that it has lupus?

Babies have some of the mother's blood products (antibodies) in them for about three months after they are born. This means that some babies develop a "lupus-like" rash after birth (neonatal lupus syndrome). There is no evidence that these children go on to develop the disease lupus and the rash usually fades over 6 months. It can be avoided by not putting the baby in sunlight. It occurs in about 10% of babies born to mothers with anti-Ro antibodies and does not occur in the absence of this antibody.

've heard that some babies born to mothers with lupus have a slow heart rate when they are born?

Some mothers have particular antibodies called anti-Ro or anti-La antibodies that may cross the afterbirth (placenta) from week 16 onwards and stick to the "electrical circuits" within the baby's heart. You will be tested for these antibodies before or when you become pregnant. If you carry these antibodies it means that there is a 1:100 (1%) chance that your baby may develop a slow heart rate in the womb. For this reason the midwife will need to check the baby's heart rate weekly from week 16. Monthly ultrasound examinations noting the fetal heart rate are also recommended. In the rare event that the baby's heart is slow, treatment and more close observation will take place under the care of specialist paediatricians even before the baby is born.

have anti-phospholipid syndrome. How does this affect my pregnancy?

This condition means that your blood is more "sticky" than it should be. Pregnancy also makes blood "stickier" in people without this condition, so that it can be a more significant problem in pregnancy than when you are not pregnant. This means that you are more prone to miscarriages than other women, as the small blood vessels of the after birth (placenta) may become blocked by blood clots, depriving the baby of essential nutrients.

This condition can also affect the well-being of the mother herself, and she is more prone to developing blood clots within the blood vessels of the body in pregnancy.

As soon as you discover that you are pregnant you must contact the hospital and be started on the appropriate medication. If you have previously had blood clots (for example deep vein thrombosis in the leg or pulmonary emboli in the lungs) you will usually be treated with aspirin and injections of heparin that you will be taught to give to yourself. You will also need very careful follow up throughout the pregnancy and for several weeks following the birth of your baby. Treatment for women with a history of recurrent miscarriages, stillbirth or pre-eclampsia associated with anti-phospholipid syndrome depends on the exact details of the previous events and the results of blood tests.

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LUPUS and pregnancy

Is pregnancy possible when you have lupus?

Yes, many lupus patients have successful pregnancies however lupus may sometimes affect fertility and lupus pregnancies can sometimes end in miscarriage or stillbirth. This leaflet is a generalised guide to "lupus and pregnancy" and it is important that you discuss any plans with your doctor before you become pregnant, so that your care can be individualised.

What should I do if I want to become pregnant?

Lupus is a disease that can potentially affect many different organs in the body and the disease can affect people in different ways. Its course may be influenced by the state of pregnancy and a pregnancy can be influenced by lupus.

As with all pregnancies, it is generally advisable to make sure that you are as fit as possible before pregnancy. It is also sensible to stop taking tobacco and alcohol and to take folic acid supplements before getting pregnant. It is advisable to consult your doctor about how stable your lupus is, as it is best to wait at least six months after a flare before becoming pregnant. This is because it has been found that the pregnancy is more likely to be successful when your disease is well controlled and stable. If your lupus is newly diagnosed it is also advisable to wait for the disease to become stable before becoming pregnant for the same reason.

Before you become pregnant it is important that all the medications that you are taking are reviewed by your doctor. Medications may sometimes have an effect upon your ability to conceive, the development of the unborn baby or your own health. Your lupus specialist will be able to make sure that you are on the best combination of drugs and that they are suitable for pregnancy.

Common medications that may be used in pregnancy include:

- Prednisolone
- Hydroxychloroquine
- Azathioprine
- Nifedipine
- Labetalol
- Ranitidine
- Paracetamol
- Calcium and Vitamin D
- Folic Acid

When should I seek additional advice about pregnancy?

If you are planning pregnancy it is advisable to receive additional advice from a doctor who specialises in lupus and pregnancy. It may be necessary to perform further tests and investigations so that you can be given the best advice about the possible risks to you and your baby.

It is particularly recommended that you should receive such counselling if your lupus has been very active recently or has affected your kidneys, brain or heart and lungs in the past. It is often necessary to perform further investigations and advise you accordingly about possible problems for you and your baby during pregnancy.

It is also recommended that ladies with anti-phospholipid syndrome receive such counselling so that they may be started on the correct treatment as soon as they become pregnant.

What should I do if I become pregnant?

As soon as you become pregnant you should call your doctor in case additional changes need to be made to your treatment. Referral to the appropriate antenatal clinic can then be made.

Women who suffer with lupus will require extra antenatal visits to the obstetric doctors compared to the routine antenatal service. The doctors will want to make sure that the baby is growing as it should and that you do not suffer any changes in the lupus disease throughout the pregnancy. Ideally, you are seen by both an obstetrician and a lupus doctor in these clinics but this is not always possible, in which case you will need to see the doctors in separate clinics.

What are the risks once I am pregnant?

Lupus is more likely to be stable during pregnancy if the disease was stable before pregnancy. Some women do have flares of lupus during pregnancy and need careful observation. The flares are usually mild but may need treating. Women at particular risk are those in whom the lupus has affected the kidneys, heart and brain in the past or at the beginning of pregnancy. Women whose disease is active when they become pregnant have the most problems from lupus during pregnancy and are likely to need additional drug therapy as the active disease can affect the development of the baby, as well as making the mother unwell. Lupus kidney disease needs particularly careful monitoring as there are no symptoms from this and, if uncontrolled, can seriously affect the health of mother and baby long-term.

Women with lupus are more likely to suffer from high blood pressure in pregnancy (pre-eclampsia) and this may occur in 1

in 5 lupus pregnancies. The risk is higher in women with anti-phospholipid syndrome (about 1 in 3 pregnancies).

Lupus and anti-phospholipid syndrome may affect the way the afterbirth (placenta) works. In early pregnancy if the placenta fails to work miscarriage will occur. Women with anti-phospholipid antibodies are particularly at risk of this complication as their blood is more "sticky". Specific treatment is advised in this group of women and tests will be performed to look for these antibodies if you have had a previous miscarriage or stillbirth.

All women with lupus have about 25% risk that the baby may not grow optimally within the womb and may need early delivery. For this reason regular ultrasound examinations of your baby are advised.

Do I have to have a Caesarean Section?

Patients with lupus do not have to have a caesarean section. However, care is individualised and if problems arise with either you or the health of the baby during pregnancy this may become necessary. The way your baby will be delivered is usually discussed in the last 3 months of the pregnancy.

What happens after I have had my baby?

Some ladies do have a "lupus flare" within the first three months after giving birth, so make sure you have an appointment with your lupus doctor within three months of having your baby. This is also a good time to review your medications again.

Can I breast feed?

It is usually safe to breastfeed if your tablets remain the same as they were while you were pregnant. Make sure that your doctor knows you are breast feeding so that he/she can ensure that your tablets remain appropriate until you stop breast-feeding.

Should I have my baby tested for lupus?

It is not a good idea to have your baby tested for lupus as there are no tests that reliably predict susceptibility to lupus. Lupus occurs in less than 10% of children born to mothers with the disease. Your genes have been mixed with your partners so there is a good chance that your baby will not inherit enough genes to cause lupus. Even if the baby inherits some genes for lupus there are other unknown factors that determine whether and when someone develops lupus, and most babies born to mothers with lupus never develop the disease, particularly if it is a boy as the disease is more common in females.