



EUROPEAN
ACADEMY OF
DERMATOLOGY &
VENEREOLOGY

Information Leaflet
for Patients

Lupus Erythematosus



The aim of this leaflet

This leaflet has been written to help you understand more about Lupus Erythematosus during pregnancy and lactation. It will tell you what it is, what causes it, and what can be done about it.

Lupus Erythematosus

What is Lupus Erythematosus?

Lupus Erythematosus (LE) is a group of autoimmune diseases which means that it is caused by the immune system attacking one's own body. These commonly run in families, along with other autoimmune diseases including diabetes, thyroid disorders, rheumatoid arthritis, and pernicious anaemia (anaemia due to a lack of Vitamin B12). As you probably know, there are different forms of LE. Some of them only involve the skin; other forms may affect internal organs (*systemic* LE). LE may get better or worse during pregnancy. When you read this leaflet you are likely pregnant; however, if you are thinking about getting pregnant, inform your clinician because careful check-ups before getting pregnant and monitoring during pregnancy are important.

LE is usually divided into three major categories:

1. Discoid LE or chronic LE - only involving the skin with scaly patches, usually in sun-exposed areas
2. Sub-acute LE – ring-shaped, red patches in sun-exposed areas
3. Systemic LE – butterfly-shaped redness on the cheeks, on sun-exposed areas of the trunk and arms, and may also involve the joints, blood, lung, kidney, heart, and other organs.

There are some other very rare forms of LE with different clinical features.

What causes Lupus Erythematosus?

LE occurs as a result of genetic predisposition, immune system abnormalities, and certain triggers such as sunlight, smoking, or certain infections. You should try to avoid exacerbating factors such as sunlight exposure and smoking

Is Lupus Erythematosus hereditary?

There is evidence that some forms of LE are genetically different disorders. Susceptibility to LE can be inherited, but not even monozygotic twins (identical twins from the same egg) will necessarily get the disease. This is due to the different immune system in each person (including each monozygotic twin), and the different provoking factors such as smoking.

Relatives of a person with LE should avoid smoking to prevent disease.

What are the symptoms of systemic Lupus Erythematosus during pregnancy?

The risk of active LE during pregnancy is increased if you have had active systemic LE in the previous 6 months, and if your medication was stopped or reduced just before or during pregnancy. In most studies of pregnant women, skin, joint and/or haematological manifestations are most commonly reported, but usually, the organs involved will be similar to those previously affected. Joint pains, skin rashes, fatigue, hair loss, and headaches are common in addition to the symptoms you may have felt previously. The risk of skin manifestation in pregnancy ranges from 25% to 90%. LE can flare at any time during pregnancy, as well as in the several months following delivery.

Many common signs and symptoms of pregnancy can easily be mistaken for signs of active systemic LE. Symptoms such as severe fatigue, hair loss, joint pain, facial redness, and headaches frequently occur during a normal pregnancy, or may be induced by treatments for other disease.

How is the diagnosis made?

Diagnosis is based on the clinical appearance, skin biopsy findings, and blood tests.

Is there any risk of LE for the newborn?

Most babies will be healthy. However, very rarely, heart disease can develop in babies whose mothers have anti-SSA/Ro and/or SSB/La antibodies. If this is the case, then your baby may require regular, special ultrasound scans during the second half of the pregnancy. In addition, your baby may develop a temporary harmless rash after sun exposure in the first few weeks of life. This rash usually disappears spontaneously within 6 months. Some of the therapeutic drugs used to treat LE may severely damage an unborn baby; therefore, it is very important to inform your clinician when you are planning a pregnancy and immediately after getting pregnant, so that these drugs can be avoided.

How should Lupus Erythematosus be treated during pregnancy?

Your LE treatment may need to be adjusted before you plan a pregnancy. This is known as pre-pregnancy counselling, and it is a good idea if you have active LE and are planning a pregnancy in the near future.

The aim of LE treatment before/during pregnancy and lactation is to prevent or reduce active disease in both you and your baby and reduce any potential harm. There needs to be a careful balance between controlling your disease and reducing harm to you and your baby during pregnancy. This decision regarding treatment during your pregnancy and while breastfeeding should be based on a mutual agreement between your clinicians (including rheumatologist, gynecologist/obstetrician, and dermatologist), yourself, and your partner.

Generally, the types of medications used to treat LE in pregnancy are the nonsteroidal anti-inflammatory drugs, corticosteroids, and immunosuppressive agents. For example, the rash in LE may be treated with low dose prednisolone (up to 10 mg/day) and/or hydroxychloroquine.

All pregnant women are recommended to take a prenatal multivitamin with at least 400 mg of folic acid each day. Folic acid is known to reduce the risk of the baby developing an abnormality in the spinal cord (neural tube defects). This is particularly important if you have been taking methotrexate prior to your pregnancy, as a deficiency of folic acid can cause neural tube defects in your baby.

Listed below are drugs that can and cannot be used for LE during pregnancy.

Drugs that can be used to treat LE in pregnancy:

- hydroxychloroquine, chloroquine, sulfasalazine, azathioprine, cyclosporine, tacrolimus.

Drugs with teratogenic effects (can cause foetal abnormalities) and should be withdrawn before pregnancy:

- methotrexate, mycophenolate mofetil, and cyclophosphamide.

Drugs which can be considered in pregnancy if needed to control active disease symptoms:

- steroid tablets (low doses);
- nonsteroidal anti-inflammatory drugs such as ibuprofen, acetylsalicylic acid, diclofenac, etc. should only be used in the first and second trimesters;
- paracetamol may be used throughout pregnancy.

Drugs which should be considered only in severe, refractory (unresponsive to treatment) maternal disease during pregnancy:

- methylprednisolone in high doses, intravenous immunoglobulin.

Drugs with insufficient documentation concerning use in pregnancy:

- leflunomide, selective COX-2 inhibitors, belimumab.

What drugs can I take during breast feeding?

The following drugs are compatible with breast feeding:

- hydroxychloroquine, chloroquine, sulfasalazine, azathioprine, cyclosporine, tacrolimus, prednisolone*, immunoglobulins.
- Nonsteroidal anti-inflammatory drugs (such as ibuprofen, paracetamol, acetylsalicylic acid, diclofenac, etc.), including also the selective COX-2 inhibitor celecoxib, are compatible only in certain doses and for short time periods.

*Maternal milk contains only 5–20% of the prednisolone dose administered to the mother, and this concentration has only negligible effects on the infant. If the prednisone dose exceeds 20 mg, breastfeeding should be delayed by at least 4 hours after the intake of the drug.

Drugs which should be avoided (limited data on breast feeding):

- methotrexate, mycophenolate mofetil, cyclophosphamide, leflunomide, COX-2 selective NSAIDs (except celecoxib and belimumab).

While every effort has been made to ensure that the information given in this leaflet is accurate, not every treatment will be suitable or effective for every person. Your own clinician will be able to advise in greater detail.