

Women's health in lupus and APS

This is the lay version of the EULAR recommendations for the management of women's health and family planning in women with lupus and/or antiphospholipid syndrome. The original publication details the recommendations on use of medications, clinical focus points and treatment options. It can be downloaded from the EULAR website: www.eular.org.

Andreoli L, et al. EULAR recommendations for women's health and the management of family planning, assisted reproduction, pregnancy and menopause in patients with systemic lupus erythematosus and/or antiphospholipid syndrome. *Ann Rheum Dis* 2017;76:476–485. [doi:10.1136/annrheumdis-2016-209770](https://doi.org/10.1136/annrheumdis-2016-209770)

Introduction

Recommendations give advice to doctors and patients about the best way to treat and manage diseases. EULAR has written recommendations on family planning, pregnancy and menopause for women who have systemic lupus erythematosus (also called lupus or SLE) and/or antiphospholipid syndrome (often shortened to APS).

The recommendations were written by a multidisciplinary team of medical specialties, other healthcare providers and patient representatives. They looked at the scientific evidence on the management of people with lupus and/or APS. They also discussed their expert opinion to achieve a level of agreement.

What do we already know?

Lupus is an autoimmune disease that can affect the joints, skin and internal organs. Lupus is often linked to APS, which is characterised by increased levels of antiphospholipid antibodies in the blood. People with antiphospholipid antibodies have a higher than normal risk of getting blood clots and pregnancy losses.

Women with lupus or APS are often diagnosed during their childbearing years. The disease can have an effect on a woman's ability to get pregnant and her chances of miscarriage. Lupus and some of the medications used for treatment increase the risk of complications during pregnancy, both for the mother and the baby.

What do the recommendations say?

Overall, there are 12 main statements or recommendations. These recommendations recognise an important need for doctors to move away from undue caution against pregnancy for women with lupus, and instead to embrace pregnancy and help their patients to have children if they want them, provided that the individual risks for each patient are discussed. The recommendations aim to help you to manage your fertility, family planning and menopause. Each recommendation is based on available scientific evidence or expert opinion. The more stars a recommendation has the stronger the evidence is.

One star (*) means it is a weak recommendation with limited scientific evidence.

Two stars (**) means it is a weak recommendation with some scientific evidence.

Three stars (***) means it is a strong recommendation with some scientific evidence.

Four stars (****) means it is a strong recommendation with a lot of scientific evidence.

- **Women should receive counselling and advice before they decide to have a baby.******

Very severe or flaring lupus, or having APS can have very serious consequences for a pregnant woman and her baby. This should be discussed before a woman decides to have a baby. Each woman's risks, such as her type of lupus and her individual treatment regime, should be assessed to help develop the best strategy for a safe pregnancy.

- Women with lupus should be counselled about the use of effective contraception.******

Your doctor should talk to you about your contraceptive options, including the pill, a coil, or an implant. Using contraceptives is especially important to prevent unwanted pregnancies when your disease is very active or when you are taking drugs that could be dangerous for a foetus. A combined pill may not be suitable if you have APS, or if your doctor thinks you are at high risk of developing blood clots. In such cases, the progesterone-only pill and a coil may be suitable options.
- Women should receive counselling about fertility.*****

If you wish to have a baby, either now or in the future, you should discuss general and disease-related risk factors with your doctor. Your lupus (especially lupus nephritis), your age, the drugs you take for your lupus, certain lifestyle exposures (such as tobacco use or alcohol consumption) may affect your ability to get pregnant. There may be lifestyle changes you can make to improve your fertility, such as limiting how much alcohol you drink, or stopping smoking.
- There are methods available to preserve fertility.****

Drugs called alkylating agents (for example, cyclophosphamide) can affect your fertility. If your doctor prescribes you an alkylating agent, he/she should also consider fertility preservation methods or drugs if you are still getting your period and might want to have a baby in the future.
- IVF and treatments to induce ovulation can be used in women with Lupus.***

As long as your lupus is stable or inactive, you can have *in vitro* fertilization (IVF) or treatments to help make you ovulate. If you have APS you might need to take medicines to prevent you getting blood clots, such as anticoagulation medications or low-dose aspirin.
- Women with lupus should be closely monitored during pregnancy.******

While you are pregnant, your doctor should assess your disease activity. This might include testing your kidney function or blood tests to check your antibody levels.
- The babies of women with lupus or APS should be closely monitored during pregnancy.***

You may need to have more ultrasound scans than normal during your pregnancy to monitor the baby's development. This is especially important during your third trimester, to make sure that your baby is the right size, and that your placenta is working properly.
- Women with lupus can take some anti-lupus drugs during pregnancy.*****

Drugs such as hydroxychloroquine, oral glucocorticoids, azathioprine, ciclosporin A and tacrolimus can be used to prevent or manage flares of your lupus while you are pregnant. Other strategies such as glucocorticoid intravenous pulse therapy, intravenous immunoglobulin and plasmapheresis can be used to manage moderate-to-severe flares. Mycophenolic acid, cyclophosphamide, leflunomide and methotrexate should be avoided because of their potential to cause malformations.
- Other drugs may be needed to limit risks during pregnancy.******

Women with lupus who are at risk of pre-eclampsia (especially those with disease that affects their kidneys, or who have tested positive for antiphospholipid antibodies) should receive low-dose aspirin. If you have APS you may need combination treatment with low-dose aspirin and heparin. Consider taking folic acid supplements when you plan to become pregnant or when you find out that you are pregnant. Check your vitamin D levels during the first trimester and discuss adequate vitamin D and calcium supplementation with your doctor.
- Women with lupus may need hormone replacement therapy when they reach the menopause.******

Hormone replacement therapy (HRT) may be helpful when you reach the menopause and if you have severe symptoms that negatively impact on your quality of life. If you have antiphospholipid antibodies

in your blood, discuss with your doctor the benefits of HRT against the risk of you getting blood clots or heart disease.

- **Women with lupus or APS should be screened for female cancers.****

If you have lupus, you may have a higher than normal risk of cervical premalignant lesions. You should attend all screening appointments. Your doctor may recommend a more intensive schedule if you are taking immunosuppressive drugs. Regarding breast, ovarian and endometrial malignancy, women with SLE and/or APS should undergo screening similar to the general population.

- **Women with lupus can have the HPV vaccination.***

The HPV vaccine protects you against Human Papilloma Virus, a sexually transmitted infection which is linked to women developing cervical cancer. If you have lupus and/or APS that is stable or inactive, you can receive the HPV vaccine as normal (according to local health policies).

Summary

Overall, the recommendations say that it is important for you and your doctor to work together to help you manage your fertility, family planning and menopause. If you have lupus and/or APS these recommendations will give you tips about what to expect from your doctor throughout your life and your pregnancies.

Recommendations with just 1 or 2 stars, which are based mainly on expert opinion and not backed up by appropriate clinical studies, may be as important as those with 3 and 4 stars.

If you have any questions or concerns about your disease or your medication, you should speak to your doctor.

Further reading

1. Bertsias G, et al. EULAR recommendations for the management of systemic lupus erythematosus with neuropsychiatric manifestations: report of a task force of the EULAR standing committee for clinical affairs. *Ann Rheum Dis* 2010; 69(12): 2074–82. [doi: 10.1136/ard.2010.130476](https://doi.org/10.1136/ard.2010.130476)
2. Bertsias G, et al. Joint European League Against Rheumatism and European Renal Association-European Dialysis and Transplant Association (EULAR/ERA-EDTA) recommendations for the management of adult and paediatric lupus nephritis. *Ann Rheum Dis* 2012;71(11): 1771–82. [doi: 10.1136/annrheumdis-2012-201940](https://doi.org/10.1136/annrheumdis-2012-201940)