

Antiphospholipid Syndrome (APS)

Information for patients



Leeds Cancer
Centre

Antiphospholipid Syndrome (APS) is a condition in which the immune system produces antibodies that increase the risk of blood clots. This can lead to blockages in veins or arteries, affecting the legs, lungs, brain or heart. In pregnancy, the antibodies can also affect the placenta, which may increase the risk of complications for the baby.

How is APS diagnosed?

APS is usually diagnosed by looking at your medical history and doing specific blood tests. Healthcare professionals look for:

- A history of blood clots or pregnancy complications, and
- Blood tests that are positive on two separate occasions, at least 12 weeks apart.

The blood tests for APS check for specific antibodies that can increase the risk of blood clots:

- **Anticardiolipin antibodies (IgG / IgM)** - antibodies that target certain fats in the blood.
- **Lupus anticoagulant (LA)** - an antibody that affects how blood clots.
- **Anti-beta-2-glycoprotein I antibodies (IgG / IgM)** - antibodies that can interfere with blood clotting and the placenta.

A diagnosis of APS is made when one of these antibodies is present at medium to high levels on two occasions at least 12 weeks apart, together with a history of a blood clot or pregnancy complication.

What causes APS?

APS is an autoimmune condition. This means your immune system, which normally protects you from infections, produces special proteins called antibodies. Antibodies help your body recognize and destroy “invaders” like bacteria, viruses, or toxins.

In APS, the immune system gets confused and makes autoantibodies that mistakenly attack your own healthy cells, specifically the fats (phospholipids) in your blood and the lining of your blood vessels.

This can make your blood more likely to form clots. These antibodies usually don’t cause problems on their own but certain triggers, such as infections, surgery, pregnancy or long periods of immobility can increase the risk of a blood clot.

In pregnancy, these antibodies can affect how the placenta attaches to the womb. They may cause tiny blood clots in the small vessels of the placenta, which can reduce the oxygen and nutrients reaching your baby. They can also cause inflammation in the placenta, which may slow your baby’s growth or increase the risk of miscarriage.

Having APS doesn’t mean you will get clots all the time. Many people go for years without problems. The risk of clots can be reduced with medication and by managing other risk factors, such as lifestyle habits or periods of immobility.

Who can get APS?

APS can affect anyone, including children but it is more common in adults aged 20 - 50. It is more common in women, especially those who have had pregnancy problems.

APS can happen on its own or with other autoimmune conditions, like lupus.

It is estimated that around one in 2,000 people may have APS, although some may not even know they have it.

There are two main types of APS:

Primary APS

- Happens on its own, without another autoimmune disease.
- The exact cause is unknown, but infections such as glandular fever or shingles can sometimes trigger it.

Secondary APS

- Occurs alongside another autoimmune condition, most commonly lupus.
- Managing the underlying condition is important to help reduce the risk of complications.

Important information

Things like immobility, surgery, pregnancy or the contraceptive pill do not cause APS but they can increase the risk of blood clots in people who already have APS.

Symptoms of APS

Symptoms can vary a lot. Some people notice nothing until a blood clot happens. Common symptoms include:

Blood Clots (Thrombosis)

- **Deep vein thrombosis (DVT):** A clot in the leg can cause swelling, pain, warmth, or redness.
- **Pulmonary embolism (PE):** A clot in the lungs can cause shortness of breath, chest pain, rapid heartbeat or coughing up blood.
- **Stroke:** A clot in the brain can cause sudden weakness or numbness, difficulty speaking, vision changes or loss of coordination.
- **Transient ischemic attack (TIA or “mini-stroke”):** Similar to a stroke but temporary, symptoms include sudden numbness, weakness, confusion or difficulty speaking, usually lasting minutes to hours.

APS and Pregnancy

APS can increase the risk of complications during pregnancy, including problems with the placenta, blood flow or the baby’s development. These may include:

- **Recurrent early miscarriages** - three or more in a row before 10 weeks.
- **Stillbirth** - loss of a baby after 20 weeks of pregnancy.
- **Pre-eclampsia** - high blood pressure in pregnancy.
- **Foetal growth restriction** - slower growth of the baby in the womb.
- **Preterm birth** - before 37 weeks.

Other symptoms of APS

Some people may notice other symptoms even if they haven't had a clot:

- **Headaches or migraines** - frequent or severe headaches.
- **Dizziness or memory problems ("brain fog")** - feeling light-headed, confused, or forgetful.
- **Feeling very tired (fatigue)** - persistent low energy.
- **Joint pain** - aching or swelling in joints.
- **Blurred vision** - temporary or ongoing changes in sight.
- **Mottled, lace-like skin rash (livedo reticularis)** - purplish or bluish patterned skin, usually on arms or legs.

With the right treatment and care, most people with APS can lead healthy, active lives. Many continue to exercise, play sports, run, cycle or go to the gym, adapting their routine as needed. Some even compete at a professional level, showing that APS doesn't have to stop you from pursuing your goals.

Treatment

The main goal of treatment is to prevent blood clots and complications. This may include:

Anticoagulants

- **Warfarin:** Warfarin is commonly used to prevent blood clots in non-pregnant patients. It is not used during pregnancy because of potential risks to the baby. Regular blood tests (INR) are required to ensure the dose is correct. Do not stop or change your warfarin without advice from your healthcare team.

- **Low molecular weight heparin (LMWH):** Given as daily injections under the skin, LMWH is often used temporarily or during pregnancy.

Regular blood tests are important to make sure treatment is working. How often you need blood tests depends on the type of anticoagulant medication you are taking.

Care and follow-up

- Patients on warfarin are monitored through anticoagulation clinics with regular blood tests to adjust dosing.
- Patients are supported with education about clot prevention, lifestyle measures and early recognition of symptoms.
- Routine follow-up with the APS Clinical Nurse Specialist ensures medication safety, reviews symptoms and reduces the risk of complications.

Care and treatment during pregnancy

During pregnancy, treatment usually involves LMWH injections once or twice daily, often combined with low-dose aspirin to help protect both mother and baby. Care is provided through a specialist consultant-led haematology and obstetric clinic, ensuring close monitoring and support throughout the pregnancy.

Follow-up and support

- Regular monitoring in the specialist haematology and obstetric clinic.
- Education and support for safe injection administration.
- Review of symptoms and medication safety.
- Advice on lifestyle measures to reduce clot risk.
- Coordination with your obstetric team for pregnancy management.

Living with APS and outlook

Most people with APS do very well when they follow their treatment plan, though some may still develop blood clots. The goal of treatment is usually to prevent blood clots or pregnancy complications, which is achieved through early diagnosis and the right combination of medications.

Medications for APS are usually taken to prevent problems before they happen. This means you may need to take them for many years, even if you feel well. They help protect your health, although like all medicines, they can have side-effects. Understanding both the benefits and risks is important.

Because blood clots can be life-threatening, stopping or changing your medication without medical advice can be very dangerous. If you are thinking about making changes, it is important to contact the team that started your medication first.

Some people may also experience symptoms like rash, joint pain, migraine, or tiredness, even if they haven't had a clot or miscarriage. This can be more common in people who have lupus alongside APS.

You can help reduce your risk and stay healthy by:

- Taking medications as prescribed.
- Attending regular check-ups with your healthcare team.
- Staying active, keeping a healthy weight and avoiding long periods of sitting or lying down.
- Not smoking and drinking plenty of water.
- Managing other health conditions, like high blood pressure or diabetes.
- Letting healthcare staff know you have APS before surgery or starting new medications.
- Talking to your doctor early if planning a pregnancy.

In summary, the outlook for most people with APS is good when the right medications are used and you stay aware of potential side-effects. Following your treatment plan and these lifestyle steps can help reduce complications and keep you healthy.

When to seek urgent help

Go to the Emergency department or call your doctor if you have:

- Sudden shortness of breath or chest pain.
- Swelling or pain in one leg.
- Sudden weakness, difficulty speaking, or vision changes.
- Severe headaches.
- Unusual bleeding or bruising.

If you are unsure whether your symptoms are serious, seek medical advice.

Support and further information

- APS Support UK
www.aps-support.org.uk



- Lupus UK
www.lupusuk.org.uk



- NHS Website
www.nhs.uk/conditions/antiphospholipid-syndrome



Contact details

Antiphospholipid Syndrome (APS) Clinical Nurse Specialist

Leeds Teaching Hospitals NHS Trust

0113 206 4024

(7am - 6pm Monday - Wednesday and 7am - 12pm Thursday)



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