

Very rarely, APS can cause clots to develop in small blood vessels in several parts of the body at once, causing damage to several organs at the same time and making you seriously ill. This is called catastrophic APS and is very rare. It's thought to be triggered by infection, trauma, medication or surgery. Many people with APS feel very well and have no symptoms. Other people with APS have symptoms like rash, joint pain, migraine and tiredness even when they don't suffer thrombosis and are not pregnant. This is especially true in people who have lupus as well as APS.

At present APS can't be cured, but the effects can be controlled. For example, treatment with anticoagulant (blood thinning) drugs can prevent both blood clots and miscarriages. The most commonly used drugs are aspirin, warfarin and heparin.

If you have APS and a history of clotting, you are likely to be given warfarin to prevent further blood clots. Warfarin is taken by mouth, you will have regular blood tests (INR) to check what effect the drug is having. The most serious side effect of warfarin during treatment is bleeding. This means your dose will be closely monitored. Warfarin can interact with a number of drugs and foods (grapefruit juice) so it is important that you are aware of this and take steps to ensure your other medication or diet won't affect your results of the blood tests.

If you've suffered miscarriages and have APS you may have increased risk of clots as well, even when you're not pregnant. If you're on warfarin and you become pregnant you will probably be changed over to heparin. This is because warfarin is potentially harmful to the baby.

It is always important that you understand the features of APS and therefore when you ask for help. You should have access to your local specialist nurse who you can call for advice. Ask your clinic for a contact number.

*This leaflet is for general information only and is not a substitute for medical advice.*



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Mon. – Fri. 9am – 1pm

# ANTIPHOSPHOLIPID SYNDROME (APS)

Patient Information Leaflet



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## WHAT IS ANTIPHOSPHOLIPID SYNDROME (APS)

Antiphospholipid Syndrome, often known as APS, is sometimes known as Sticky Blood Syndrome or Hughes syndrome after a Doctor who researched the condition in the 1980's. APS can cause blood clotting in the arteries and veins and is also a major cause of recurrent miscarriage. It can occur on its own or alongside a condition called LUPUS.

The two main symptoms are **blood clotting** and **pregnancy problems**. Blood clotting can occur:

- ◆ In the veins
- ◆ In the arteries
- ◆ In the brain

In pregnancy, APS can cause recurrent miscarriage. APS can also cause other pregnancy problems such as high blood pressure (pre-eclampsia), small babies and early deliveries.

APS is an **autoimmune disease**, which means that it's caused by your immune system attacking particular parts of the body and producing symptoms. **APS is not hereditary**

In people with APS, the immune system produces harmful **antibodies called antiphospholipid antibodies (aPL)**. These aPL affect cells in the blood and in the walls of the blood vessels in such a way that the blood becomes 'sticky' and more likely to clot inside the vessels. Clotting inside vessels is called **thrombosis**. In pregnant women aPL can also affect the womb and the **placenta** in a way that can make the baby grow more slowly and

increase the risk of miscarriage. There are a number of other factors which are unrelated to APS, that make it more likely for you to develop blood clots, including:

- ◆ Smoking
- ◆ Immobility (related, for instance, to the thrombosis seen after long-haul flights)  
The contraceptive pill
- ◆ Genetic factors – there may be a family
- ◆ history of clots, miscarriages, other autoimmune diseases such as lupus or thyroid problems.

Diagnosis is made from the clinical history of blood clots and/or pregnancy loss, confirmed with one or more of three particular blood tests:

- ◆ The anticardiolipin test
- ◆ The lupus anticoagulant test
- ◆ The anti-beta-2-glycoprotein 1 test

Although these tests measure broadly the same thing, around 20% of people with APS will have a negative test result in one or the other, so one test alone could miss the diagnosis. The diagnosis is made if there has been a blood clot or miscarriage **and** positive blood test on two occasions at least 12 weeks apart.

APS can be treated with its effects controlled, often with anticoagulation drugs:

- ◆ If you have APS and a history of clotting, you will probably be given Warfarin (an anticoagulation drug) to prevent further clots.
- ◆ If you have had a number of miscarriages but no history of clotting, you will probably be given low-dose aspirin during pregnancy to prevent another miscarriage. You may be given injections of **heparin** as well.

- ◆ If you have suffered both miscarriages and clotting you will probably be given, **warfarin** when you are not pregnant, but this will be changed to heparin when you are pregnant and aspirin will be added.

Other problems sometimes associated with APS include:

- ◆ **Heart problems:** the heart valves may thicken and fail to work, or the arteries may narrow because their walls get thicker, leading to **angina**.
- ◆ **Kidney problems:** APS can cause the narrowing of the blood vessels, including those serving the kidney's, resulting in high-blood pressure.
- ◆ **Infertility:** testing for antiphospholipid antibodies is becoming routine in infertility clinics.
- ◆ **Skin problems:** some people develop a blotchy rash, often seen on the knees or arms and wrists, with a lacy pattern (known as **livedo reticularis**)
- ◆ **Low platelet count:** platelets are small cells in the blood which are involved in the control of bleeding. Some people with APS have very low platelet levels – often there are no symptoms, although people with very low counts may bruise easily or experience strange or excessive bleeding.