NHS
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# Antiphospholipid syndrome (APS)

**This leaflet has been written to provide you with information about antiphsopholipid syndrome.**

## What is Antiphospolipd syndrome?

Antiphospholipid syndrome (APS) is a condition where people have an increased tendency to develop blood clots caused by the body's immune system. For some patients, APS is associated with SLE (systemic lupus erythematosus), another immune condition, but it can also occur on its own. The main features of APS are clots in the veins (e.g. a deep venous thrombosis or DVT) or arteries (e.g. a stroke), so the condition may be called thrombotic (i.e. clot related) APS. Some people mainly develop thrombotic problems during pregnancy, which is called obstetric antiphospholipid syndrome (OAS); this is discussed in a separate information leaflet www.royalberkshire.nhs.uk/media/mgmlhiwn/antiphospholipid-syndrome-aps.pdf.

## How is APS diagnosed?

Diagnosing APS is complex. The diagnosis relies upon the combination of having a thrombosis and blood test results positive for specific antibodies. It is also important for a doctor to consider if there are other reasons why you may have a blood clot present and if there are other symptoms or findings that suggest APS.

Criteria have been developed from research studies to try to make sure that patients treated for APS all definitely have the condition. These criteria are helpful for assessing whether patients have APS, but the diagnosis always requires judgement from an experienced doctor.

Features in addition to a blood clot suggesting a diagnosis of APS include:

- Low platelets (< 130 x $10^9$/L) (small cells in the blood that are involved in the clotting process)
- Heart valve thickening or growths called vegetations (identified using imaging scans)
- A lace- or net- like skin rash called livedo reticularis or livedo racemosa
- Biopsies or scans showing typical changes of APS affecting small blood vessels in the kidney, lung, heart or adrenal gland.

Testing for APS in the laboratory is done with blood tests, which look for the presence of several different antibodies:

- Anti-cardiolipin IgG and IgM
- Anti-β2-glycoprotein-1 IgG and IgM
- An antibody-related change in the way blood clots in a test tube, called a lupus anticoagulant.

Interpreting these tests is quite complex and quite a lot of normal people (up to around 5 or 10 out of 100 patients) will have detectable antibodies. Often these are at low level and come and go over a period of weeks.

To diagnose APS, the antibody needs to be at a high enough level (generally > 40 Units), and these levels must also persist over at least 12 weeks.

For the lupus anticoagulant, laboratories will generally report the test as positive or negative, although some results reported as positive may be weak and there are several causes of 'false positive' results, so it is advised that the significance of any positive result is discussed with a haematologist.

Once a diagnosis of APS has been made it is generally not helpful to keep repeating the antibody tests as we do not know if this reliably predicts any change in the behaviour of the condition.

## What is the treatment for APS?

The main treatment of thrombotic APS is anticoagulation (often called blood thinners). Without treatment, the risk of having another thrombosis for patients with APS is high.

- For patients who have had an arterial thrombosis and patients who have 3 positive antibody tests, the preferred treatment is warfarin. This is because in clinical trials, warfarin resulted in fewer people having strokes than those on some newer tablet treatments.
- For patients with a history of a venous blood clot who have only one or two positive types of antibody test, we do not know for sure yet if warfarin or one of the newer treatments is better and the choice of anticoagulant will be discussed with you on an individual basis.
- For patients with features of APS beyond the blood clots, and especially those who also have SLE, drugs to suppress the immune system such as hydroxychloroquine may be recommended by the Rheumatology team. In more severe cases, antibody treatments that suppress the immune system, such as Rituximab, may be recommended.
- Patients with a low platelet count may be recommended by a haematologist to use drugs used for immune causes of low platelet counts to reduce the risk of bleeding.

## Where can I access further information?

Please speak to the team looking after you if you require more information.

There is also information about APS on the Versus Arthritis website:
https://versusarthritis.org/about-arthritis/conditions/antiphospholipid-syndrome/

To find out more about our Trust visit www.royalberkshire.nhs.uk

**Please ask if you need this information in another language or format.**

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