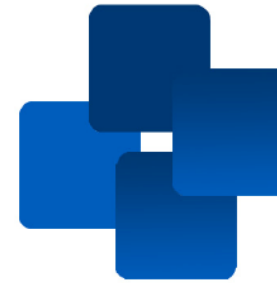
East and North Hertfordshire
NHS Trust

Patient Information

Antiphospholipid Syndrome (APS) in Pregnancy



Introduction

Antiphospholipid syndrome (APS), also known as Hughes syndrome or 'sticky blood' syndrome, is a disorder of the immune system that can lead to an increased risk of blood clots developing inside blood vessels.

For women with APS, this may lead to complications during pregnancy. Early diagnosis and treatment of APS can lead to a successful pregnancy and your specialist teams will support you with this.

What causes APS?

Antibodies are normally made by the immune system to fight infections. In some diseases, the body forms antibodies against itself by mistake. This is known as an **autoimmune** disease.

It is thought that in APS, the immune system accidentally makes antibodies against a type of fatty molecule found in your cells. These are called **antiphospholipid antibodies**.

Antiphospholipid antibodies activate blood clotting and stimulate inflammation, which increases the chances of a blood clot forming in the wrong place. This is known as **thrombophilia**.

If a clot forms inside a blood vessel, it can block the blood supply to different parts of the body, leading to problems. The type of blood vessel affected will determine the nature of the problem encountered. Arteries are vessels which carry blood to our organs, while veins are the vessels which carry blood away from the organs and back to the heart.

APS is not usually passed down through families. Most cases will occur randomly, although if someone in your immediate family has APS you may have a slightly increased risk of developing it. It is not necessary to screen babies or children for APS when the mother has the disorder or antibodies.

What are the symptoms of APS?

The symptoms of APS depend on where a blood clot has formed.

Most commonly, blood clots form in veins. For example:

- **Legs** - a blood clot may form in the deep veins of the leg causing it to become swollen and painful. This is known as a deep vein thrombosis (DVT) and may rarely be related to APS, if no other cause is found.
- **Lungs** - a blood clot may form somewhere in the body, and break off to block a blood vessel entering the lungs. This can lead to shortness of breath, difficulty in breathing and pain on breathing in. This is called a pulmonary embolism (PE) and may rarely be related to the presence of APS antibodies, if no other cause is found.

Less commonly, blood clots can form in arteries. For example:

- **Brain** - a blood clot forming in the blood supply to the brain can cause a stroke or 'mini-stroke', also known as a transient ischaemic attack (TIA). This is only likely to be related to APS if you are under the age of 50.
- **Heart** - a blood clot forming in the blood supply to the heart can cause a heart attack.

Other symptoms of APS include:

- **Migraines** - these are common in APS and the cause is not fully understood.
- **Skin changes** - these include rashes and ulcers, usually on the legs or arms.

Why does APS have an effect on pregnancy?

The placenta is the organ that grows alongside the baby in the womb during pregnancy. It provides the growing baby with nutrients and oxygen through a special blood supply.

It is thought that the tendency to form blood clots in APS may increase the chances of blood clots forming in the placenta. If clots form, the blood supply to the baby is reduced or the baby may not attach properly onto the lining of the womb.

The formation of blood clots during pregnancy may lead to consequences, including:

- **Recurrent miscarriages** - This refers to having three miscarriages in a row, without a normal pregnancy in-between. It is important to emphasise that 1 in 4 pregnancies end in a miscarriage before 12 weeks, so they are extremely common. Often the cause is not found. If you have had three miscarriages in a row and no cause can be found for this, your doctor may test you for APS.
- **Pre-term birth** - Where the baby is born early, before 37 weeks of pregnancy. This occurs in approximately 10-20% of APS pregnancies (that is 10-20 of every 100 pregnancies in women affected by APS).
- **Pre-eclampsia** - A condition leading to high blood pressure and protein in the urine during the second half of pregnancy. This occurs in approximately 10-20% of APS pregnancies.
- **Intra-uterine growth restriction (IUGR)** - Where the growth of the baby slows down or stops during the pregnancy. IUGR occurs in approximately 10-30% of APS pregnancies.

- **Placental abruption** - Where the placenta detaches from the wall of the womb too early, before the baby has been delivered. It is a very rare complication, occurring in less than 1% of all pregnancies, but is around 1.5 times more common in women with APS compared to women without.
- **Stillbirth** - Where the baby dies in the womb after 24 weeks of pregnancy, but still requires delivery. Stillbirth is an extremely rare complication but appears to be slightly more common in women with APS.

How common is APS?

It is thought that APS occurs in up to 1% of the population, although each person with the condition is affected differently.

It is around four times more common in women than men and is usually seen in younger or middle-aged women (before they have gone through the menopause).

APS can occur together with other autoimmune diseases, such as systemic lupus erythematosus (Lupus, or SLE) and rheumatoid arthritis; this is known as **secondary APS**. If APS occurs by itself, this is called **primary APS**.

How is APS diagnosed?

You will not be diagnosed with APS unless you have symptoms consistent with APS **and** a positive blood test.

Who is tested for APS?

- Pregnant women who have **not had any** complications, will **not** be offered testing routinely.
- If you have had some of the symptoms of APS in the past, you may be offered a test.
- If you have had three miscarriages **in a row**, with no normal pregnancies in between, you may be offered a test for APS.
- Patients who already have an autoimmune disease, such as SLE, will usually be offered an APS test by their specialist, when considering pregnancy.

APS is usually diagnosed using two blood tests at least 12 weeks apart. There are three types of antiphospholipid antibodies: **lupus anticoagulant**, **anticardiolipin antibodies** and **anti-beta 2 glycoprotein antibodies**. You will be tested for all three using the same blood sample.

It is important to do the blood tests twice as sometimes people can have antibodies in their blood briefly which then go away again, for example, after an infection. You will not normally need any scans.

People with APS generally test positive for antiphospholipid antibodies on their blood tests. However, some people **without** APS may also test positive for the antibodies. Having antiphospholipid antibodies in your blood does not mean that you will definitely develop blood clots or other features of the syndrome in the future.

How is APS treated?

It is important to try and change anything which might increase your risk of forming a blood clot. The best way to do this is by having a generally healthy lifestyle, for example by:

- Stopping smoking.
- Exercising and maintaining a healthy weight.
- Eating a healthy diet.
- Reducing your alcohol intake.

If you would like help with any of these, please speak to your GP.

You may also be given medications, such as aspirin tablets or heparin injections. These medications help to stop new blood clots forming and help to prevent existing blood clots from getting any bigger. In pregnancy, you may be offered one or both of these medications from conception until up to 6 weeks after you deliver. Your specialist team will decide which medication is best for you.

'Blood-thinning' tablets, such as warfarin, are sometimes used to treat APS but they are not suitable for use during pregnancy or if you are trying for a baby. If you are already taking warfarin and you fall pregnant, please let your specialist know as soon as possible so that they can advise you how to stop your warfarin safely and change to an option that is safe in pregnancy.

If you already know that you have APS and you are thinking about trying for a baby, please speak to your specialist first as it may be necessary to start you on medications **before** you start trying.

It is important to diagnose APS early as correct diagnosis and treatment can lead to a successful pregnancy. Your specialist team will help to make an individualised treatment plan to support you throughout your pregnancy.

Further Information

NHS Choices
https://www.nhs.uk/conditions/antiphospholipid-syndrome/

APS Support UK
http://aps-support.org.uk/

Tommy's
https://www.tommys.org/pregnancy-information/pregnancy-complications/antiphospholipid-syndrome-aps

Patient
https://patient.info/health/blood-clotting-tests/antiphospholipid-syndrome

Versus Arthritis
https://www.versusarthritis.org/about-arthritis/conditions/antiphospholipid-syndrome/

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