MISCARRIAGE
ASSOCIATION
The knowledge to help

Antiphospholipid syndrome (APS) and pregnancy loss

We have written this leaflet for women and their partners,[1] who have had recurrent miscarriages and have also been diagnosed with antiphospholipid syndrome (APS).

But you might be reading it because you are about to have investigations following recurrent miscarriage, or simply because you want to know more about this cause of miscarriage.

Whatever your circumstances, we hope that you find this leaflet helpful.

What is antiphospholipid syndrome?

Antiphospholipid syndrome (APS), sometimes known as Hughes syndrome, is a disorder of the immune system which affects the blood and its ability to clot. An overactive immune system produces antiphospholipid antibodies (aPL), which cause the blood to clot too quickly both in veins and arteries.

How is it diagnosed?

You will have blood tests to check for antiphospholipid antibodies (aPL). They will actually test the blood for three types of antibody. The reason for the three tests is that they measure aPL in different ways which means that one test alone could miss the diagnosis:

- lupus anticoagulant (LA)
- anticardiolipin antibody (aCL)
- anti beta-2 glycoptein I antibodies

Don’t be confused by the first of these, “lupus anticoagulant”, which is a rather misleading term.

It doesn’t mean you are being tested for lupus. And it doesn’t mean you have an anticoagulant (blood thinner) in your blood.

If any of the tests are positive, they should be repeated.

This is because aPL can occur just for a short time due to infection or some medicines.

Another reason for repeating the test is that antibody levels vary over time.

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[1] We often use the words ‘woman’ or ‘women’ in this leaflet but we recognise that the person who has had the physical loss may not identify as such.

Laboratories differ in the way they measure their tests, so it is not possible to provide a single guideline indicating the positive and negative ranges. However, your results should show whether you are negative or positive, according to your laboratory's specific classification.

You will be diagnosed with APS if you have:

- two positive tests for aPL, taken at least 12 weeks apart and one or more of the following:
    - a history of three or more first trimester miscarriages, with no other cause being found
    - previous pre-eclampsia and intrauterine growth restriction, resulting in a baby being born before 34 weeks.
    - a second or third trimester pregnancy loss or stillbirth
    - a previous thrombosis (blood clot)

How does APS cause pregnancy problems?

Antiphospholipid antibodies (aPL) can cause different problems at different stages of pregnancy in different women.

In some women with aPL, in the first 13 weeks, the antibodies can prevent the pregnancy from embedding properly in the womb, increasing the chances of an early miscarriage.

In the second and third trimesters of pregnancy (from 14 weeks gestation until birth), aPL in some women can cause blood clots in the placenta, This can lead to poor blood and oxygen supplies to the baby, causing poor growth, pre-eclampsia or even stillbirth.

Some women with aPL will have no problems in pregnancy at all.

Researchers are still trying to find out more about the link between APS and pregnancy loss.

> **“It was a relief that there was finally a name for the problem, some explanation for my miscarriages.”**

Can APS cause any particular symptoms or problems?

If you are diagnosed with APS, you may well have no other symptoms or conditions. Some people with APS, however, have one or more of the following:

Skin Approximately one fifth of people with APS have a blotchy, mottled appearance to their skin

A tendency to bruise easily
This is unusual. Occasionally women with APS have a low platelet count (platelets are cells in the blood that help the blood to clot)

Blood clots in the vein
The most common blood clot in the vein is a deep vein thrombosis (DVT) of the leg.

Joint pain There may be a history of joint pain or swelling in the joints (arthritis).

Neurological problems
Some people with APS have migraine-like symptoms or brief loss of vision or balance, or even stroke.

Abdominal or heart disease
Rarely, APS can cause liver, heart or kidney problems, due to blood clots. If you are diagnosed with APS, you may be referred for tests such as an echocardiogram of your heart, to check that you are healthy.

How is APS treated?

Unfortunately, there is no cure for APS, but treatment can improve your chances of having a healthy future pregnancy.

Once you have an APS diagnosis, you will likely be given daily doses of aspirin or daily injections of a drug called heparin – sometimes you might be prescribed both. These aim to prevent blood clots and are safe to take during pregnancy.

Sometimes, where a person has APS and has experienced a blood clot (thrombosis) already, the blood thinner Warfarin is prescribed. However, it is not recommended during pregnancy as it carries a small risk of causing birth defects. If you have been taking Warfarin and become pregnant, don't simply stop taking it – speak to your GP or specialist so they can change the medication, usually to heparin.

You will continue to take medication throughout a future pregnancy and for several weeks after birth to help prevent blood clots. Never stop taking you medication unless your health professional tells you to.

> **“Although it's not easy sticking a needle in your tummy every day when pregnant, at least it feels like you're doing something to help, something different to last time.”**

Your feelings

Miscarriage can be a very unhappy and frightening event in any circumstances. But if you have experienced recurrent miscarriage, you may have found it much harder to bear than your first or even second loss. You may wonder whether you'll ever have a baby.

In addition, the investigation process itself can be stressful. You may have had to wait to be referred for tests, then waited for your appointment – and then had to wait for the tests to be repeated over several months.

What does having APS mean for the future?

You might be relieved that you've been told you have APS. Finally there's an explanation for your miscarriages and a treatment plan for the future. There is good reason to feel positive – having treatment for your APS makes it much more likely that you'll have a healthy pregnancy.

On the other hand, you may find it difficult to feel positive. You have been disappointed so many times before that it can be hard to begin another pregnancy with any hope that it might succeed.

And trying not to be too hopeful may feel like the best way of protecting yourself in case things go wrong again.

Many couples go through a mixture of hope and anxiety – up one minute and down the next – and you might too.

Once you are pregnant your medical team will keep a close watch on you and your baby during the whole pregnancy. You will usually have more appointments and scans than normal, this can be stressful but will help to make sure you have a healthy pregnancy. And if you have someone you can call on when you are feeling anxious, this can help too. (See page 7 for some suggestions.)

> **“I'm glad they've found out what caused my miscarriages – but it sounds pretty frightening too.”**

What if things go wrong?

Sadly, even with expert care and treatment, you might miscarry again, or lose the baby at a different stage of pregnancy.

This might be because the treatment hasn't prevented your APS from harming the pregnancy. In this situation, your doctor may try a different treatment next time.

Or it might be that the pregnancy ends for a different reason, not because of the APS. This might be a chromosome problem, where something goes wrong very early in the baby's development. In this case, the treatment for APS couldn't help.

Either way, you may need time before you can begin to think about whether you would like to try again. And you might need extra support.

What about other health problems?

If you are diagnosed with APS, your doctor should give you more information about other possible health risks related to blood-clotting problems. You will probably be advised to have regular check-ups at a specialist clinic in the future.

That might feel like a mixed blessing. All you were hoping for was an explanation for your miscarriages and a treatment to help prevent it happening again. Now you have to think not only about having a healthy pregnancy, but also about your general health.

It can be difficult to cope with this extra burden – indeed, you might feel it's all very unfair. But it does mean that you will have the best possible care to help you and your baby in pregnancy and to help you stay healthy now and in the future.

> **“Being told I had APS made me worry about my own health outside of pregnancy too. It was important to get specialist advice on things like long-haul flights.”**

Support and information

You might find it helps to talk to someone who can understand what you are going though.

The Miscarriage Association
offers support and information through a staffed helpline: phone, live chat, email and direct messaging; online and in-person support groups, an online forum and private Facebook groups.
Tel: 01924 200799
www.miscarriageassociation.org.uk

> **“We all find different ways to cope. I think talking to others on the Miscarriage Association forum helps you to not feel so alone.”**

All the organisations listed below offer support and information about pregnancy loss and/or APS. Your doctor may also find these useful sources of information.

APS Support UK
supports anyone affected by APS. Aims to achieve earlier diagnosis and better treatment by raising awareness and helping fund research.
www.aps-support.org.uk

Thrombosis UK
works to raise awareness and promote research into thrombosis and offers impartial, factual information through its leaflets and on its website.
www.thrombosisuk.org

APEC – Action on Pre-eclampsia
offers support and information on pre-eclampsia through its helpline, leaflets and website.
https://action-on-pre-eclampsia.org.uk/

Need to talk to someone who understands?

Call on 01924 200799.
Email us at info@miscarriageassociation.org.uk
Start a live chat via our website: miscarriageassociation.org.uk

Monday, Tuesday and Thursday: 9am - 4pm.
Wednesday and Friday: 9am - 8pm.

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The Miscarriage Association
T: 01924 200799
E: info@miscarriageassociation.org.uk
W: www.miscarriageassociation.org.uk

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