

The Miscarriage Association



Acknowledging Pregnancy Loss



Antiphospholipid syndrome and pregnancy loss

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Introduction

This leaflet has been written primarily for women who have experienced recurrent miscarriages and have been diagnosed as having Antiphospholipid syndrome. This condition is also known as Antiphospholipid antibody syndrome, Hughes' syndrome or APS and in this leaflet we will usually call it APS. If you have APS but have not experienced miscarriage, please don't assume that this is bound to happen to you – it isn't.

You may be reading this leaflet because you are about to have investigations following recurrent miscarriage, or simply because you want to know more. If so, please understand that we have written it as if we are talking to someone who has both conditions.

Whatever your circumstances, we hope that you find this leaflet helpful. We will begin by talking about Antiphospholipid syndrome and then go on to focus on pregnancy loss.

Antiphospholipid syndrome – what is it?

In general, a syndrome means a combination of signs, symptoms or test results. Antiphospholipid syndrome (APS) is the association between antiphospholipid antibodies (often written as aPL), blood clots in the veins and arteries (doctors call these thromboses) and pregnancy problems, which include pregnancy loss (miscarriage). If someone with APS has another autoimmune disease as well, such as systemic lupus erythematosus (SLE), then she is said to have secondary APS. If someone has APS alone, without any other autoimmune diseases, she is said to have primary APS.

Diagnosing the syndrome

Diagnosing APS can be confusing and difficult, as there are two types of tests that must be performed for two different types of antibody (this is explained further in the next paragraph). Both can be carried out in different ways and different hospitals use different tests. Antibody levels can also differ over time, so sometimes two tests done in the same centre produce different results. Occasionally it can happen that a woman tests positive for APS in one centre and negative in another. Sometimes the antiphospholipid antibody can occur just for a short time as a result of infection or certain medication, so for this reason it is recommended to carry out the test twice, at an interval of about 6 weeks.

Recognising antiphospholipid antibodies (aPL)

Antiphospholipid antibodies were first recognised over 40 years ago as causing false positive results in a test for infection. Today, the lupus anticoagulant (LA) and anticardiolipin antibody (aCL) are the types of antibodies most commonly detected in routine laboratory tests. Don't be

confused by the term "lupus anticoagulant"; it doesn't refer to systemic lupus erythematosus (SLE) and it is also not an anticoagulant. It doesn't mean you have lupus.

Usually the LA makes blood clots more likely. Very rarely, the LA may produce bleeding by producing low levels of prothrombin, a factor in the blood needed for clotting.

You can have aCL (anticardiolipin antibodies) without having an increased risk of thrombosis. This can happen, for example, with certain kinds of infection (e.g. chickenpox or malaria) or when taking certain medicines (e.g. phenothiazines, hydralazine, phenytoin).

The Diagnosis

To be diagnosed with APS, a woman has to have had two positive tests for aPL within six weeks **and** either one or both of the following:

- a previous thrombosis (blood clot)
- pregnancy problems such as pregnancy loss, intra-uterine growth restriction (IUGR) or pre-eclampsia

This means that it is not necessary to have all the symptoms for a diagnosis so, for example, some women with APS have recurrent pregnancy loss but no history of thrombosis, and vice versa.

When people started describing APS, they focused on the link between aPL and late miscarriage - that is, second trimester loss due to the death of the baby. Now, however, we know that these antibodies also make other pregnancy problems more likely.

Current research suggests that the aPL antibodies can cause different problems at different stages of the pregnancy. In the first 13 weeks, the antibodies can prevent the pregnancy from embedding properly in the uterus (womb), increasing the chances of an early miscarriage. In the second and third trimesters of pregnancy (from 14 weeks gestation until birth), it seems likely that blood clots in the placenta lead to poor blood and oxygen supplies to the baby, causing poor growth, pre-eclampsia or, rarely, death of the baby.

Clinical signs

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 mottled appearance to their skin

A tendency to bruise easily This is caused by a condition called "Thrombocytopenia", which is a reduced platelet count (platelets are cells in the blood that help the blood to clot and are measured as a standard part of a routine blood screening test).

Blood clots in the vein The most common blood clot in the vein is a deep vein thrombosis (DVT) of the leg. It might happen when there are also other risk factors (such as the oral contraceptive pill) or without any obvious trigger.

Joint pain This may be a history of joint pain or diagnosed arthritis.

Central nervous system problems Some people with APS have migraine-like symptoms or an occasional 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.

Management of APS

Although much work has been done on how to detect APS and the conditions with which it may be associated, there is still not much information available on how it should be treated or managed. Most hospitals do not see large numbers of APS patients, but there are some centres with a particular interest in APS and you may want to discuss a referral to a specialist centre with your GP or hospital doctor. These centres are conducting research into management and follow-up care for APS patients.

If APS patients have a thrombosis (blood clot), it is usual practice to prescribe treatment with warfarin, which reduces the blood's tendency to clot. The aim of the treatment is to ensure that patients have a steady level of blood thinness, measured as INR units. Patients attend special anticoagulant clinics to have their INR levels checked and some may also monitor their levels at home.

What if I don't have any symptoms?

If you have been found to have aPL, but you have not had previous thrombosis or miscarriage; or even if you have had one or two early losses, but not three, it is not very clear what the best treatment is. Some doctors prescribe 75 mg a day of aspirin, as it is low-risk and it has been beneficial in preventing other types of thrombosis. It is also recommended to avoid smoking; not to use the combined oral contraceptive pill or hormone replacement therapy; to try not to get dehydrated; and to avoid being immobilised (e.g. in bed) for long periods of time. Your specialist doctor can advise on extra precautions to avoid blood clots if you need surgery or if you plan long-haul airline travel.

In conclusion the diagnosis and management of APS can be complex and requires the support of specialists with an interest in thrombosis.

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APS and pregnancy loss

As we said earlier, Antiphospholipid antibodies can cause the following problems for the developing pregnancy:

- recurrent first trimester loss (up to 13 weeks)
- late pregnancy loss (from 14 to 40 weeks); this includes stillbirth
- pre-eclampsia
- placental abruption
- intra-uterine growth restriction

The main focus of this leaflet is recurrent miscarriage but it may also be useful for women who lose a baby at a later stage in pregnancy. Please see page 7 for a list of specialist support and information services, including those for pre-eclampsia and stillbirth.

Miscarriage

Miscarriage can be a very unhappy and frightening event. Feelings of grief and loss are common, and so is anxiety about what might happen in another pregnancy. Fortunately, for most women who miscarry, their next pregnancy will be successful and the pain of their loss will be eased, at least in part, by the arrival of a new baby.

Recurrent miscarriage

If you have experienced recurrent miscarriage, however, you may have found it much harder to bear than your first or even second loss. It can be devastating to lose one baby after another and this can be made worse by feelings of guilt (*It must be something I did*) or sheer hopelessness (*I'm never going to be able to have a baby*). It can be hard to cope with family, friends or colleagues who are pregnant or have new babies. What's more, you may find that just as you need increased support from those around you, people find it harder to know what to say or how to comfort you.

Women and their partners are often desperate to know the cause of their miscarriages. You may have been referred to a specialist quite quickly, or you may have been frustrated by the length of time you had to wait, or the number of miscarriages you had to experience, before being referred for specialist investigation.

We know that after a second or third trimester loss associated with APS, there is a strong likelihood that it will happen again in a future pregnancy. For that reason, tests for antiphospholipid antibodies should ideally be done after one late loss in order to reduce the risk of recurrence.

Investigations

In most illnesses, when someone is referred by their doctor for further investigations, s/he hopes that no major problem will be found. In the case of miscarriage, however, most couples are hoping for a positive finding; they want an explanation for their losses and they also hope that this will mean treatment which will resolve the problem. Nevertheless, hope can be mixed with anxiety about the diagnosis and about what it might mean for the future. In addition, the investigation process itself can be stressful, especially when tests need to be repeated over several weeks. You may find it helpful to get additional support around this time.

Your diagnosis – what does it mean for the future?

Now that you have been diagnosed with APS, you will be offered treatment in your next pregnancy (and possibly before that). Because this is a relatively new area, treatments can vary. If you are being treated in a specialist centre, you may also be invited to take part in a research study which may benefit you or other people with APS. You will be given full information before you decide whether or not you want to take part.

Your diagnosis may come as a great relief, that you have an explanation for your miscarriages and a treatment plan for the future. There is good reason to feel positive: the chance of a healthy pregnancy has been shown to increase considerably with treatment.

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 the only way to protect yourself against another loss.

For many couples, there will be a mixture of hope and anxiety and this is understandable. Regular check-ups during your pregnancy may help reassure you that all is developing as it should and if you have someone you can call on when you are feeling anxious, this can help too. See page 7 for a list of specialist organisations.

If things go wrong

Sadly, even with expert care and treatment, you may miscarry again, or lose the baby at a different stage of pregnancy. This might be through treatment failure, where the treatment does not prevent your condition from harming the pregnancy. In this situation, your doctor may try a different approach next time. Or it might be that the pregnancy ends for a reason unconnected to your condition, such as a chromosome problem in the early stage of the baby's development. You may need time before you can begin to think about whether you would like to try again. You may find it helpful to seek additional support around this time.

Finally

When you were having investigations following your miscarriages, your main concern was being able to have a healthy pregnancy and a baby. Now that you have been diagnosed with APS, you will be given more information about other possible health risks and may be advised to have regular follow-up in the future.

You may feel that this diagnosis is something of a mixed blessing: on the one hand, you have more hope of having a healthy pregnancy, but on the other hand you will need regular check-ups at a specialist clinic. It can be difficult to cope with this extra burden – indeed, you may feel it's all very unfair – but it does mean that you will have the best possible care to help you stay healthy, both immediately and in the future.

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Useful resources

Sources of support and/or information

If you would like to talk to someone who can understand what you are going through, you may find it helpful to contact one or more of the following organisations, which offer support and information about pregnancy loss and APS. Your doctor may also find these useful sources of information.

The Miscarriage Association

c/o Clayton Hospital, Northgate, Wakefield WF1 3JS

Tel: 01924 200799

e-mail: info@miscarriageassociation.org.uk

Website: www.miscarriageassociation.org.uk

The Miscarriage Association is a national charity which offers support and information on pregnancy loss (up to 24 weeks). You can talk to helpline staff or to a support volunteer who has experienced pregnancy loss and APS. They can offer support after pregnancy loss, while awaiting and during investigations, when you are considering whether to try again and during pregnancy after a previous loss or losses.

Lifeblood: the thrombosis charity

PO Box 1050, Spalding PE12 6YF

Tel: 01406 381017

Website: www.thrombosis-charity.org.uk

Lifeblood works to raise awareness and promote research into thrombosis and offers impartial, factual information through its leaflets and on its website.

Hughes Syndrome Foundation

The Rayne Institute, St Thomas' Hospital, London SE1 7EH

Tel: 020 7188 8217

e-mail: hsf@btconnect.com

Website: www.hughes-syndrome.org

Offers support, information and education about Hughes syndrome as well as supporting research into the condition.

APEC – Action on Pre-eclampsia

84-88 Pinner Road, Harrow, Middlesex HA1 4HZ

Tel: 020 8863 3271

e-mail: enquiries@apec.org.uk

Website: www.apec.org.uk

Offers support and information on pre-eclampsia through its helpline, leaflets and website.

SANDS – the Stillbirth and Neonatal Death Society

28 Portland Place, London W1B 1LY

Tel: 020 7436 5881

e-mail: support@uk-sands.org

www.uk-sands.org

Offers support and information after late miscarriage, stillbirth and neonatal death, through its helpline, leaflets and website.

The Association of Early Pregnancy Units

www.earlypregnancy.com

Works to promote excellent standards of care in early pregnancy assessment and care and offers a guide to Early Pregnancy Units across the U.K..

The Recurrent Miscarriage Clinic, St Mary's Hospital, London

www.recurrentmiscarriage.co.uk

Provides information about recurrent miscarriage causes, investigations and treatment.

Useful reading

"Miscarriage: what every woman needs to know", by Professor Lesley Regan. Orion Books 2001 (2nd edition).

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