



ABOUT HUGHES SYNDROME

What is Hughes syndrome and how can it affect you?

Known medically as the antiphospholipid syndrome (APS) and more colloquially as 'sticky blood', Hughes syndrome is an autoimmune disease 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.

We are not yet sure why the immune system becomes overactive and attacks itself, but increasing clinical evidence indicates there is probably a genetic tendency which is triggered in people with the condition. These triggers could include viral infections, such as glandular fever and shingles, and also other well known precipitants of blood clots such as immobility, dehydration, surgery, the oral contraceptive pill and pregnancy.

With Hughes/antiphospholipid syndrome, the blood clotting can affect any vein, artery or organ in the body and the consequences can include potentially fatal conditions such as heart attacks, strokes, and DVT. In pregnancy, the antibodies can cause miscarriage, pre-eclampsia, small babies, early deliveries and stillbirth. It can also cause more low-grade symptoms such as headaches, migraines, dizziness, memory problems and fatigue.

Not all people with Hughes/antiphospholipid syndrome will go on to develop blood clots and/or pregnancy problems and, while some people can live virtually symptom-free, others are severely affected in their day-to-day living. Much more vital research is needed before we can answer these questions.

There are two main types of Hughes/antiphospholipid syndrome: primary and secondary. Primary is when the condition is not linked to any other disease and develops in isolation, while secondary is when it develops along with another autoimmune disorder, such as lupus

People from all ages, including children can have Hughes/antiphospholipid syndrome, but it tends to mainly affect the 20-50 year old age group and women more so than men. It is difficult to gauge how common it is as people are often undiagnosed or misdiagnosed and, as yet, there have been no large scale epidemiological studies carried out. However, evidence from small scale studies indicates a conservative estimate of at least 1% of the population – in the UK alone that means over 600,000 people are affected by Hughes/antiphospholipid syndrome, making the disease more common than Parkinson's Disease and equivalent to multiple sclerosis.

The good news is that Hughes/antiphospholipid syndrome is both potentially preventable and treatable if recognised in time. Being diagnosed as early as possible and treated correctly seems to have a direct bearing on how well patients will feel in the future. The majority of patients can lead a normal life provided they continue with their medication but, unfortunately, a small number of people will continue to experience blood clots despite having extensive treatment – the reasons for this are still not known.