Family and friends: helping people understand APS

People respond in different ways to being diagnosed with antiphospholipid syndrome (APS) – you may feel like hiding the news from everyone, but helping your family and friends learn more about your condition can mean that you receive more support and understanding.

It can be difficult for your close ones to come to terms with the fact that you have a potentially life-threatening long-term condition, and that you may not be able to do some of the things you did previously.

Remember - your family and friends see you just as you have always looked, and cannot possibly know what is going on inside your body.

The main difficulties in understanding APS are:

- You can have good days and bad days
- You look so well
- It affects people differently

Most people with APS will have good and bad days so it should help your family and friends if you explain that, on a bad day, you could be affected with a number of symptoms such as:

- 'Brain fog' – a very common symptom – where you have difficulty thinking clearly and have memory and/or word-finding problems
- Reduced energy levels brought on by fatigue
- Constant headache or migraine, sometimes with visual disturbances
- Dizziness and balance problems
- Arthralgia (joint pain) usually in the hands, feet and knees

These bad days tend to pass quickly, so let your loved ones know that and ask for their patience and support during these times.

We are all different and while for some people APS is not debilitating, for others it can be a disabling condition.

However it affects you, the disease can have a considerable impact on your quality of life due to its unpredictable nature. It can be very stressful living with a condition that could potentially have serious complications, and most people with APS will experience some level of psychological distress at times.

Talking about your condition with your family and friends can help relieve some of this burden, and also help them understand how you are feeling.

Try to remember that you are still the same person even though you have been diagnosed with APS, but your lifestyle may have to be different from now on.