



SELF HELP

Family and friends: helping people understand your condition

People respond in different ways to being diagnosed with Hughes/antiphospholipid syndrome – 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 chronic 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 Hughes/antiphospholipid syndrome are:

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

Most people with Hughes/antiphospholipid syndrome 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 Hughes/antiphospholipid syndrome is not debilitating, for others it can be a disabling condition. However it affects you, the illness 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 Hughes/antiphospholipid syndrome 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.

Remember that you are still the same person now that you have been diagnosed with Hughes/antiphospholipid syndrome, but your lifestyle may be different from now on.