

The doctor will change your medication to a different anticoagulant that is safe. Using proper treatment, women with APS have about the same risks as other women during pregnancy.

If you have had a blood clot (i.e., stroke, heart attack, DVT) and tested positive for APS, do not let a doctor take you off of an anticoagulant without seeing a doctor familiar with APS for a second opinion. Sometimes it is necessary to change the type of anticoagulant for surgical or dental procedures. Some doctors will treat you with anticoagulants for six months and then take you off anticoagulation "to see what happens." Abruptly stopping anticoagulation will cause an increased chance that you will have another clot. The clot can easily result in a heart attack, stroke or Catastrophic Antiphospholipid Antibody Syndrome (CAPS). Antiphospholipid antibodies may be detected in individuals who are completely asymptomatic, but, in some patients, these antibodies may be associated with a rapidly progressive disorder that can be fatal. In addition, the blood clots that can be seen with these antibodies can be fatal, depending on how large they are or which blood vessels are affected.

## How Can You Help?

There are many ways you can help the APS Foundation of America, Inc. We welcome volunteers in the areas of fundraising, advocacy, support group experiences, monetary donations, or the purchase of APS gear through our website at [www.apsfa.org](http://www.apsfa.org), or through our CaféPress store at [www.cafepress.com/apsfoundation](http://www.cafepress.com/apsfoundation). The APS Foundation of America, Inc. is a non-profit organization. Your donations are needed greatly to help us provide awareness, support, and education of this disease. We need your enthusiasm and monetary support to help our individuals, families, friends, and care givers battle the long-term consequences caused by APS. Thank you in advance for your support and time. Please contact us at [apsfa@apsfa.org](mailto:apsfa@apsfa.org) or at 608-782-2626 for more information.

Please send donations to:

**APS Foundation of America, Inc.**  
Post Office Box 801  
La Crosse, Wisconsin 54602-0801

We also accept PayPal donations via our website. The email that it is registered under is [donate@apsfa.org](mailto:donate@apsfa.org).

*We thank you for your support!*

*The APS Foundation of America, Inc. is not intended to replace standard doctor-patient visits, physical examination, and medical testing. Information given to members are only opinions. All information should be confirmed with your personal doctor. Always seek the advice of a trained physician, in person, before seeking any new treatment regarding your medical diagnosis or condition. Any information received from the APS Foundation of America, Inc. is not intended to diagnose, treat, or cure. This brochure is for informational purposes only.*

***If you think you may have a medical emergency, call your doctor or 911 immediately.***

A team of people contributed to this publication. Information was adapted from various websites, books, and other media sources. Please contact us at [apsfa@apsfa.org](mailto:apsfa@apsfa.org) for a complete list of sources. This pamphlet was assessed at draft stage by doctors, allied health professionals, an education specialist and people with APS. A non-medical editor rewrote the text to make it easy to understand and an APS Foundation of America, Inc. medical editor is responsible for the content overall.

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# Antiphospholipid Antibody Syndrome & You

## APS & You

This pamphlet was created for Antiphospholipid Antibody Syndrome (APS) patients as a supplement to the APS Booklet. It provides simple suggestions to get the best outcome as possible.

## Take Your Medication

It is very important to take your medicine every day. Try to take your the medicine at the same time each day for consistency. You may want to get a pillbox that holds at least one week's supply of the pill(s) or to mark it on a calendar when you take your medicine. This will help you to know when you have taken your pills. Do not take two doses in one day if you have forgotten your dose.

## Start a Medical Journal

Start a medical journal to keep track of any events and your Warfarin (Coumadin<sup>®</sup>) levels (INR). List the date, time, symptom, how long it lasted, severity, and anything you think that might have triggered it. For rashes and color changes start a photo journal. This is always helpful to show to the doctors, since the rash or color change may be gone by the time you have an appointment to see one. Write down any questions you may have and take the journal with you to your appointments.

## Coping With APS

APS treatment is life long. Treatment of blood clots caused by APS outweighs the small side effects by treatment.

Most of the time people with APS will appear on the outside just as they did before they were diagnosed. Because of this, it may be difficult for family and friends to understand that you have a life threatening illness and that you just can't do some of the things that you could before. They can't see what is going on with your body and this can become quite frustrating on both ends.

In some cases you may want a therapist to help you adjust. Any person with a chronic illness is at risk of being depressed. In some cases this progresses to clinical depression. It is very important to discuss your mental health with your doctor as well as your physical health.

The APS Foundation of America, Inc has a place on the Internet where you can communicate with others who have this disease. You can find our support forum at [www.apsforum.com](http://www.apsforum.com). You are the only one who knows exactly how you feel. Others with the same disease are very understanding and support groups of some kind can make your life much fuller. Your immediate family and children should be told about your disease, how it affects you, what it means to them as well as what you may have to expect of them in support.

The good news is: many people with proper treatment live normal full lives. Others may find their lives changed forever due to APS, but a positive attitude will mean that life can still be worthwhile and fulfilling as the correct treatment prevents further problems.

## Safety When Traveling

Long trips, especially by air, have some clotting risk even for non-APS people. It is important for people with APS to get up and walk around at least every couple of hours. On long car trips stop at least every two hours and walk. Drink plenty of water and wear

compression stockings to help reduce your chance of DVT. If you plan on traveling during a scheduled INR draw, you may want to get it done before you leave. If you are going to be away for an extended period of time, you may need to schedule an INR draw where you're traveling to.

Be sure to buy traveler's insurance to protect your plane tickets in case of a medical emergency. Also, before leaving find out if your medical insurance company provides coverage in a different state or country.

## Other Points To Consider

You may notice you bruise more easily or little cuts will bleed longer when you are taking Warfarin (Coumadin<sup>®</sup>). Injuries can be more serious when on anticoagulants and care should be taken during any activity that can result in injury. Contact sports are not recommended.

If you should injure your head while on anticoagulants, go directly to the Emergency Room. Your brain is very sensitive to bleeds while on anticoagulants. Be sure they know you are on anticoagulants and tell them what your most recent INR was. This information is important and they will need to know this up front before a doctor comes to see you.

You should have a Medic Alert<sup>®</sup> bracelet and wear it at all times. You can order one through Medic Alert<sup>®</sup> at [www.medicalert.org](http://www.medicalert.org). A bracelet is the most visible, the easiest and the most recognized however, there are also necklaces and other types available.

If you are trying to get pregnant or are pregnant it is very important to let your doctor know immediately. Continued use of Warfarin can cause birth defects.